



## **The Road to Rehabilitation Series**

### **Part 1:**

## **Pathways to Comfort: Dealing with Pain & Brain Injury**

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**Brain Injury Association of America**  
**"The Voice of Brain Injury"**

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## **Introduction**

Everyone has experienced pain at one time or another. Although most individuals find it bothersome, many of them are able to continue going about their activities of daily living (ADLs) despite the pain. However, for some persons, the pain they experience can be severe, causing a person to avoid some, most and/or all of their activities. This brochure will attempt to provide the reader with a greater understanding of pain and how it can be improved in an effort to assist individuals with more disabling pain who also are challenged with recovery from brain injury.

Pain can be viewed as either acute or chronic. Acute pain typically has a cause that easily is explained and usually improves as the physical cause is treated properly. In contrast, chronic pain persists beyond the expected healing time and continues despite appropriate physical improvement in the affected area of the body. Chronic pain affects millions of Americans and can disrupt job performance, as well as causing problems in relationships with family members and other individuals.

When chronic pain occurs in a person with brain injury, it can be very distracting and interfere with the focus and effort this individual needs to make in facing the many challenges of the recovery process. Approaches to pain management in persons with brain injury tend to be similar to approaches for individuals who have not sustained a brain injury. While this can be helpful for some individuals with traumatic brain injury (TBI), cognitive limitations following brain injury are wide ranging and are not always taken into account. If proper steps are not taken to account for each individual's specific limitations and strengths, there may be a substantial reduction in the effectiveness of the pain management approach.

Many people believe that the amount of pain they feel is related directly to the severity of injury or is a result of increasing physical problems at the site of injury. If the pain increases over time or spreads to other areas of the body, they may think their injury is becoming worse. However, this may not be the case, particularly if it is not supported by medical findings. Instead, the increasing and spreading pain may be associated with the impact of a number of other factors including: (1) emotional functioning, (2) personality traits, (3) past learning experiences, (4) the way others respond to the person's behavior and (5) deconditioning from limited movement. Assessment of these other factors sometimes can be helpful in making recommendations to improve the person's control over the pain.

## **Types of Pain**

Pain can be viewed as either *acute* or *chronic*. Acute pain usually has a cause that easily is explainable and well-defined (i.e., a blow to the head resulting in headache, swelling, discoloration or other obvious injury to the painful area). The amount of pain corresponds to the level of discomfort and it usually improves as the physical cause is identified and treated accurately. Although responses to acute pain vary from person to person, usually over time the report of pain and the person's response to it improves in relation to the improvement of the physical injury.

In contrast to acute pain, chronic pain persists beyond the expected healing time for a particular injury and/or illness. This means pain continues despite appropriate treatment and physical improvement in the affected area. Individuals with chronic pain typically show pain in excess of that which can be explained by physical causes alone. Not only can this pain be widespread, sometimes it may not make sense medically because it may not remain at the original site of injury nor may it stay in related areas of the body. In most cases, the pain and the disability it creates remains the same or worsens, rather than slowly and steadily improving as expected.

## **Pain and Brain Injury**

A person who has sustained a brain injury faces many challenges. These challenges include returning to work or school, family responsibilities and social activities with newly acquired problems in thinking skills (i.e., cognition) as well as in physical and emotional/behavioral functioning. The difficulties a person with brain injury faces can be even greater when pain is involved. The pain can emerge as headaches, neck and shoulder pain, lower back pain and/or pain in other body areas. The pain may be so intense and bothersome that the person withdraws from work, family and social activities. Unfortunately, this could result in a situation that may be out of proportion to the degree of physical, cognitive and emotional consequences of the brain injury itself.

Pain experienced by individuals with mild brain injury may prevent them from attempting to return to everyday activities despite being ready for a gradual, safe return as a result of improvement in cognitive functioning. This not only serves to lengthen significantly the time before returning to activities, but it also may contribute to hesitancy and reduced self-confidence when later attempting to resume activities. In contrast to people with mild brain injury, individuals with moderate to severe brain injury may deny or minimize the effects of their deficits. For these people, pain may reduce both awareness of their deficits and their incentive to work on improving these deficits by causing them to focus too much on their pain.

The greater the deficits sustained from the brain injury, the greater the emphasis will be on family members to participate in the reduction of pain behaviors in the person with brain injury. An individual who has sustained a brain injury may face a variety of cognitive and/or psychosocial limitations including:

- A lack of awareness of deficits
- A lack of insight into the effect a particular impairment may have on everyday functioning
- Reduced attention and/or concentration
- Decreased short-term memory and learning, sequencing, judgment and reasoning
- Decreased initiation
- Apathy or indifference
- Impulsivity
- Anger and/or irritability
- Impatience and/or frustration
- Restlessness
- Withdrawal
- Suspiciousness and/or distrust of others
- Reduced self-awareness

These limitations may serve to restrict the person's ability to carry out recommendations for managing the pain consistently and reliably. Generating a list of cognitive and psychosocial impairments and making the necessary treatment adjustments is important. A professional experienced with individuals with brain injury will be very helpful in this regard.

Success in the management of chronic pain depends in large part on the person's understanding of the pain and his/her incentive and drive to improve the pain. As a result, when dealing with individuals with brain injury, it is necessary to take into consideration the individual's specific limitations. First, the individual must understand the source of the pain. The pain should be explained in a manner that compensates for any cognitive deficits. Explanations should be provided

in brief, concrete sentences that utilize more than one modality (i.e., verbal statements and visual aids). The specific cognitive strengths and weaknesses of the individual also should be considered in these explanations to improve understanding and potential cooperation. An understanding is needed of the benefits of treatment and how the treatment plan will help achieve these benefits.

It also is important to note that some pain medications can exacerbate cognitive deficits in attention, memory and other areas. Minimizing and, if medically feasible, eventually eliminating use of narcotic medications will allow the person with brain injury to maximize his/her potential to participate successfully in a pain management program.

Arranging for a neuropsychologist to provide instruction to pain management specialists on the relevant effects of the person's brain injury on his/her treatment will be important. Some questions that need to be answered include: *Can the person with brain injury focus long enough to participate in a pain program? Can the person recall the behavioral and physical exercises? Can the person follow an exercise sequence? Can the person follow the logic of the treatment plan? Are there any significant personality or emotional factors that need to be accounted for?*

Additionally, the neuropsychologist may help the person with brain injury and his/her family to: (1) understand possible obstacles to participating successfully in a pain management program, (2) outline steps for compensating for cognitive limitations when working with pain specialists and (3) help establish appropriate incentives for the person with brain injury to enhance participation in the pain management program.

Individuals with brain injury are not all the same—each person presents his/her own unique combination of strengths and weaknesses. Tailoring pain management interventions to meet the specific needs of each individual will be important for success.

### **How Pain is Measured**

Pain may be measured in different ways. One common way is to have the person rate the pain on a scale of zero to ten, both at rest and when performing different activities. The individual also may be asked to perform certain physical tasks to test his/her capability to carry out each task with the reported pain. Unfortunately, none of these ways of measuring pain provides an unbiased, objective measure since they rely on the person's own perceptions of the pain.

In addition, pain felt from a particular injury can vary from person to person as a result of different tolerance levels to the same degree of injury. These differences in pain tolerance are associated with a variety of biological, psychological, social and emotional differences among people. The variability of pain tolerance from person to person and the lack of an unbiased way to measure pain complicate the professional's understanding of the person's pain and can lead to disagreements between the person experiencing the pain and the treating professionals. In cases of disagreements, professionals may request psychological and functional capacity evaluations. These evaluations help to: (1) increase the professional's understanding of the person's pain complaints, (2) increase the functional difficulties that may result from the pain and (3) identify how best to treat and manage the person's pain.

### **Chronic Pain Syndrome**

Chronic pain is believed to involve a variety of factors, including psychological components. Some individuals have observed that chronic pain begins as physical pain that has failed to resolve or has become worse. The person then develops unhealthy ways to deal with the physical pain, creating problems in daily functioning or making existing problems worse. The person then can develop

“chronic” pain that cannot be explained medically. More recently, chronic pain has come to be viewed as a complex experience or syndrome involving sensory, cognitive, motivational and emotional components. For example, psychological influences such as increased daily stress, a perception of having little control over events in one’s life and lower levels of psychological well-being have been associated with more frequent pain episodes and sometimes a greater severity of pain.

Sleep and appetite disturbances—along with the side effects of excessive pain medication—intensify the disability that results from chronic pain. As time goes by, the person may become depressed and preoccupied with normal changes in bodily functioning and may worry about experiencing new illnesses. The individual can develop a tendency to view all activities in terms of how much pain will be experienced. This can lead to a cycle of helplessness and despair, often accompanied by anger toward professionals who never seem to be able to cure the pain. In turn, professionals lose patience with the person with persistent pain who appears to have limited medical justification for these complaints. Pain becomes the main focus of the person’s life. Interests and social activities are given up, resulting in withdrawal from family and friends. Isolation from others can contribute to the development of alcohol and medication abuse. Pain can become an excuse to allow the person to avoid stressful activities and conflicts. The whole process can become cyclical and result in a greater focus on pain, less support by family and friends and greater isolation and dependence.

There are several major components of *chronic pain syndrome*. These include a significant decrease in any kind of activity, as well as selective inactivity (i.e., claiming that certain tasks—usually unpleasant ones—are too painful to perform, while equally demanding, albeit enjoyable activities do not result in similar complaints of pain). Abuse of alcohol and medications can be common. Some reports have estimated that as much as 90% of individuals with chronic pain syndrome abuse alcohol and/or medications. Although any sort of medication may be involved, the narcotic, sedative and minor tranquilizer medications most often are abused.

Typically, these drugs provide little pain relief and increase the person’s challenges in daily functioning by causing: (1) thinking and memory problems, (2) decreased activity, (3) increased bed rest and (4) inconsistent sleep patterns. These problems may be worse for people with brain injury who have less tolerance for these drugs. Individuals who grow dependent on narcotic medications take them regularly every three to four hours and show a classic pattern of awakening in the middle of the night when they have overslept their supply and go into low-level withdrawal. Narcotics and sedatives can be helpful in acute pain. However, daily consumption for more than two to four weeks encourages tolerance and dependence and, in the long-term, may help maintain the pain problem.

Another component of chronic pain syndrome is excessive use of health care resources, including multiple medical examinations and unnecessary surgery that prove to be of no lasting benefit. Psychological changes involving depression also are common. Depression is exacerbated by extended periods of inactivity and overuse of narcotics and sedatives. Overuse of narcotics and sedatives can result in memory and other cognitive problems that confuse these individuals, increase their anxiety and reduce their ability to cope with pain.

The involvement of a work-related disability or a history of work difficulty prior to the injury may serve to decrease the person’s motivation to improve the pain in order to escape an unpleasant work situation or avoid possible unemployment. Finally, in some studies, the presence of an attorney in workers’ compensation cases has been associated with failure to return to work after pain treatment.

When issues of litigation and compensation are involved, the person's focus can change many times to having been "wronged" and to restoring his/her pride rather than focusing effort on adjusting to and improving present problems with pain.

### **Managing Chronic Pain**

Acute pain requires minimal intervention and resolves naturally. Chronic pain syndrome can be a disabling diagnosis that may require multidisciplinary assessment and treatment. Many times, it never may be eliminated completely. As a result, pain management strategies are based on one ultimate and constant objective—*the reduction of pain, not its total elimination*. If the person experiencing the pain and all of the professionals who treat the individual do not make this the goal, frustration will grow, resulting in failure to coordinate treatment efforts in a successful manner. The treating professionals must make this the goal because treatment can break down if even one team member begins to alter treatment as a result of changing the goal to "elimination" of the pain. Also, if the person changes his/her expectations to complete elimination of the pain, odds are that the person will experience continued disappointment even though treatments may be reducing the pain significantly.

Always, the goal of chronic pain management is to reduce the pain and improve the person's ability to cope with the pain that remains. Never is the goal to eliminate the pain completely. Reasonable outcomes include:

- Decreased medication use
- Fewer physician visits
- Decreased attempts of seeking alternate physicians by both the individual with pain and the referring physician
- Fewer hospitalizations and emergency department visits
- Lower costs of maintaining pain care
- Improved flexibility
- Greater endurance
- Increased strength
- Improved functioning at home
- Improved interaction with family and friends
- Return to employment

The *disease model of illness* does not explain or provide an adequate basis for treating chronic pain syndrome given its reliance on a physical basis for the pain, while ignoring the psychological, social and legal factors that appear to contribute to chronic pain syndrome. As a result, other approaches to understanding and treating chronic pain syndrome have been utilized.

One common approach uses the *operant model of pain*. In this model, pain is viewed as a *learned behavior*. A psychologist or neuropsychologist with training and experience in behavior management can help professionals use this approach with the person with chronic pain. Other approaches help the person to identify inappropriate and unhealthy beliefs about pain and provide strategies to deal more effectively with pain behavior. Several techniques such as: (1) relaxation training, (2) hypnosis, (3) stress management, (4) attention-diversion strategies and (5) biofeedback may be used in conjunction with the operant model and other approaches.

Regardless of the preferred mode of treatment, a good pain management program usually includes several basic elements. First, chronic pain involves not only pain, but also several other problems such as depression, deconditioning, unhealthy learned responses to the pain, functional disability

and dependence on medications. The presence of these other challenges may make it necessary to receive treatment from several different types of professionals in a coordinated manner. Receiving pain medications from a physician or heat treatments from a physical therapist may provide temporary relief from the pain. However, the other problems associated with chronic pain syndrome often result in the pain level returning to its initial level of severity. Thus, obtaining treatment from a multidisciplinary pain clinic or rehabilitation center or—if these are not available—a well-coordinated effort between the primary physician and other necessary professionals, likely will provide the best opportunity for success.

A second element involves managing emotional distress. Chronic pain commonly involves depression which can contribute to alcohol and other substance abuse, inactivity, loss of employment and poor self-esteem. Medication and psychotherapy can be very helpful in improving mood, enabling the person to participate more effectively in pain management treatments and preventing some of the associated problems from developing.

A third element consists of medication monitoring with the goal of eliminating unnecessary medications, particularly narcotics and sedative-hypnotic agents given their potential for abuse.

A fourth element involves efforts to increase exercise and activity level to combat deconditioning and its harmful effects on pain and overall functioning.

A fifth element involves a combination of *operant* and *cognitive-behavioral approaches*. This may include programs designed to increase healthy behaviors and reduce unhealthy pain behaviors. It also may include strategies to identify and replace inappropriate thoughts about pain, as well as relaxation training—possibly with biofeedback or hypnosis—to provide a sense of self-control and mastery over pain. Finally, it may include training in problem solving, communication skills, assertiveness and social skills. A sixth element is emphasis on the impact family members and significant others can have on managing pain behavior. Teaching family and friends how to change specific ways they interact with their loved one who has sustained a brain injury in order to produce more healthy behavior cannot be emphasized enough.

For the person with brain injury, another element is the identification of cognitive deficits and their underlying causes (i.e., impaired memory, medication effects). Professionals then can take appropriate steps to improve and/or work around these limitations to allow the individual to maximize the benefits from the pain management program. If the person with brain injury and pain is interested in returning to work and has the cognitive capacity to pursue this interest, a final element involves making professionals aware of past employment history along with obtaining aggressive vocational rehabilitation and follow-up.

## **Resources**

The management of chronic pain in persons with brain injury requires multidisciplinary assessment and treatment. The team of healthcare professionals that may be involved in managing chronic pain in persons with brain injury includes:

- Physiatrists
- Primary care physicians
- Anesthesiologists specially trained in invasive procedures for the treatment of subacute and chronic pain
- Physical and occupational therapists
- Neuropsychologists or psychologists
- Neuropsychiatrists or psychiatrists

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- Registered biofeedback technicians
- Insurance preapproval staff
- Nurses
- Social workers
- Nutritionists

This is a list of possible members of a treatment team and does not mean that all of these professionals are needed in all or even most cases. However, it is essential for the team to include a physician, neuropsychologist and/or other professional with an understanding of brain injury in order to provide guidance in working around the person's limitations from the brain injury. It also is very important that each professional involved in treatment establish short- and longterm goals before proceeding with specific treatments. Further, they should coordinate their efforts with all other treating professionals. This will be facilitated by active involvement on the part of family members who can make an effort to encourage communication among professionals.

Investigating treatment alternatives in the local area and ensuring that a coordinated effort is being made among all professionals providing treatment are two ways of enhancing the chances of success. Checking with the local hospital for a nearby pain treatment center or finding out if they have a behavioral medicine department that treats chronic pain in an individual with brain injury is a good start. Also, some insurance carriers have their own pain management programs and asking them about their plan may be helpful.

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**Road to Rehabilitation Series**

1. Pathways to Comfort: Dealing with Pain and Brain Injury
2. Highways to Healing: Post-Traumatic Headaches and Brain Injury
3. Guideposts to Recognition: Cognition, Memory and Brain Injury
4. Navigating the Curves: Behavior Change and Brain Injury
5. Crossing the Communication Bridge: Speech, Language and Brain Injury
6. Mapping the Way: Drug Therapy and Brain Injury
7. Traveling Toward Relief: Dealing with Spasticity and Brain Injury
8. Journey Toward Understanding: Concussion and Mild Brain Injury



## **The Road to Rehabilitation Part 2: Highways to Healing: Post-Traumatic Headaches & Brain Injury**

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## Introduction

Headache and neck pain are the most common physical complaints following concussion (i.e., mild brain injury) and are experienced early after injury by up to 70% of persons with these types of injuries. Headache also occurs after more severe brain injury. However—for some reason as yet unidentified—it tends to be a much less common phenomena. Although post-traumatic headaches may be quite persistent, they have not been found to relate to the severity of injury. Often, persons will seek medical care following concussion, head/cranial trauma and/or cervical whiplash injury only to be diagnosed with *posttraumatic headache* (PTHA). This brochure will provide readers with an overview of issues related to diagnosis, treatment and outcome of PTHA.

The majority of headaches following brain injury (i.e., cerebral trauma), as well as cranial and cervical trauma generally are benign and do not require surgical treatment. Occasionally, there are complications that occur— particularly after more severe brain injury—that may cause headache requiring surgical intervention. Certain more serious conditions including subdural and epidural hematomas (i.e., blood collecting between the brain and the skull), communicating hydrocephalus, tension pneumocephalus, brain abscesses and carotid cavernous fistulas (i.e., abnormal communication between the venous blood flow and arterial blood flow going to the eye) may require surgical treatment. Through appropriate clinical examination and additional diagnostic tests, these types of conditions can be ruled out.

## Sources of Head Pain

There are multiple sources of head and neck pain, both inside and outside of the head. Interestingly, the brain itself is not a source of pain. Inside the skull, the major structures responsible for pain are the thin coating over the brain at its base (i.e., the dura), the venous sinuses, blood vessels and certain cranial nerves (specifically II, III, V, IX and X). Outside of the skull, the major structures that may produce pain after trauma include the skin, muscles, nerves, arteries, joint capsules, cavities within the head (i.e., sinuses, eyes, ears, nose and oral cavity), cervical nerves (first through third) and the thin layer of pain sensitive tissue coating bones in the head and neck (i.e., the periosteum).

Newer information about chronic pain has provided insights into mechanisms such as central desensitization and “wind-up”, two still poorly understood phenomena, which may account for some of the more complex and confounding chronic cases of PTHA that do not have a readily identifiable set of pain generators.

## Causes of Head Pain

Headache typically results from six major causes:

- Displacement of structures within the skull
- Inflammation (the source may be intracranial, extracranial or cervical)
- Decreased blood flow and/or metabolic changes
- Increased muscle tone in the head or neck
- Inflammation/irritation of the thin layers of tissue “coating” the brain (i.e., the meninges).
- Increased pressure within the skull

## PTHA: Not a Diagnosis

PTHA is not a diagnosis, but rather a symptom of an underlying disorder. All too often, the treating physician makes a diagnosis of PTHA and no further elaboration is made relative to the problem causing the pain. Often, PTHA is treated as neurovascular or migraine headache when,

in fact, the great majority of these headaches (probably at least 75%) are not due primarily to migraine type problems.

It is important to understand that headaches following brain injury do not mean necessarily that the pain is originating from the brain—since the brain actually is insensate (i.e., unable to sense pain). There are several different types of injuries that may lead to development of pain generators of headache. To fully understand your injury, your doctor may ask you questions about the mechanism of injury responsible for the initial insult including the types of restraints used, speed of the vehicles (as applicable), history of direct blows to the head or body, as well as history of cervical whiplash injury. Specifically, your doctor should inquire regarding clues to the presence of the three “Cs”:

- Cerebral (i.e., brain) injury
- Cranial or cranial/adnexal trauma (i.e., damage to the head or structure in the head but outside the brain) and
- Cervical acceleration/deceleration (CAD) insult (also called whiplash injury)

### **What Questions Should be Asked?**

One of the major clues for your doctor regarding the cause of your headache should be the *headache symptom profile*. Your doctor also should inquire as to your pre-injury personal and family history of headache. Just because an individual experienced headache pre-injury does not mean that he/she could not develop a different type of headache or a worsening of the pre-injury condition following trauma. The major questions that need to be asked by your doctor to search for clues relative to understanding your headache can be expressed nicely in the mnemonic “COLDER” (i.e., Character, Onset, Location, Duration, Exacerbation and Relief).

In order to develop a more complete understanding of the headache problem, other questions that need to be asked include the: (1) frequency and severity of pain, (2) types and magnitude of associated symptoms, (3) presence of preheadache aura, (4) degree of functional disability associated with headache episodes and (5) time of day that the headaches come on. With the aforementioned information, the clinician then is armed with enough information to conduct a thorough clinical examination to ascertain a more specific conclusion as to the origin of the headache condition.

### **The Physical Assessment**

Adequate physical examination is paramount to an appropriate diagnosis and should include inspection, palpation, auscultation (i.e., the process of using a stethoscope to listen for sounds produced in the body cavities such as the chest and abdomen to detect abnormalities) and percussion (i.e., the process of striking or tapping a part of the body with quick, sharp blows), as appropriate.

However, the neurologic exam should be a centerpiece of this assessment. Adequate examination of cranial and cervical structures including palpation of the head, neck and shoulders is a crucial but often overlooked aspect of the exam. As Goethe once said, “We see what we look for, we look for what we know.” This saying particularly is relevant to the physical assessment of the individual with PTHA, as clinicians without adequate training in PTHA will tend to approach assessment from a specialty point of view rather than one based on holistic pain assessment. For example, the neurologist will tend to endorse migraine, and the physiatrist musculoskeletal pain generators. On the other hand, the ER doctor will see pain as pain and have a propensity to prescribe narcotics to get the person “back on their feet” without exploring the pain generators responsible for the symptom of pain.

## **Major Headache Subtypes**

Including the potential surgical conditions previously mentioned, the major types of headaches observed following trauma include:

- Musculoskeletal headache
- Tension-type headache
- Neuroma/neuralgic (i.e., nerve) headache
- Post-traumatic sympathetic nerve dysfunction
- Neurovascular (i.e., migraine) headache
- Other rare causes of headache including seizure disorders, pneumo-cephalus (i.e., air in the head), cluster and paroxysmal hemicrania (severe, typically one-sided, headaches)

## **Musculoskeletal Headache**

The most common cause of head discomfort or headache after trauma—and often one of the most overlooked—is referred to as musculoskeletal pain from the neck and secondarily cranial adnexal structures (structures in the head, but not the brain itself). The most common variant of this type of pain generator is cervical myofascial pain syndromes (MPS) associated with cervical acceleration-deceleration injury.

Another form of musculoskeletal pain that should be considered is that of temporomandibular joint dysfunction which often is seen predominantly as myofascial dysfunction of the masticatory (i.e., chewing) muscles (see TMJD below). Certainly pain also may be generated from skull and/or facial fractures resulting from trauma. Musculoskeletal headache that is cervicogenic (i.e., arising from the neck) in origin typically presents symptoms of pressure and tension, often with a cap-like distribution. The headache tends to worsen with stooping, bending or exertion and may be associated with other symptoms such as dizziness, sensitivity to light (i.e., photophobia), sensitivity to sound (i.e., phonophobia) and even imbalance.

It is important that the treating physician have a good understanding of the relevant examination findings in persons with MPS, including how to: (1) do an appropriate muscle exam, (2) find trigger/tender points and (3) appreciate certain clinical features such as “twitch responses” and/or “jump signs.” Understanding referred pain patterns from trigger points— particularly for cervical muscles with higher propensity for injury following whiplash—is critical. Associated symptoms, as well as factors which may perpetuate MPS disorders following injury, also need to be well understood by the treating physician.

## **Cervical Somatic Dysfunction**

Cervical somatic (vertebral) dysfunction often is seen in association with cervical myofascial dysfunction. This condition is significantly under appreciated by the vast majority of clinicians evaluating and treating this patient population. Subtle vertebral rotations, anterior as well as posterior, may cause pain, both local and referred, into the head through multiple mechanisms. The contribution of somatic dysfunction to headache remains controversial. Manual and/or manipulative therapy can be quite effective when used alone or in combination with other interventions to assist in “resetting” bony/osseous structures.

Conservative short-term and/or infrequent symptomatic treatment utilizing manual medicine therapy is helpful when clinically indicated. It is not recommended as the sole long-term intervention because such treatment does not address the underlying problem(s) at hand. Treatment instead should focus on strengthening weak axial/spinal musculature, decreasing axial asymmetries and improvement of posture.

### **Temporomandibular Joint Dysfunction**

Temporomandibular joint dysfunction (TMJD) is a controversial consequence of “whiplash” type injury. It is this clinician’s experience that injury to the chewing muscles is a much more common problem than injury to the joint itself. However, it should be noted that with significant muscle injury the joint might become involved secondarily.

TMJD is over-diagnosed relative to its causal relation with trauma. Many persons have pre-existing TMJD disorders that may get worse following significant cervical injury.

Management of TMJD, either related to masticatory muscle MPD and/or joint involvement, generally is conservative involving prescription of non-steroidal anti-inflammatory agents and muscle relaxants, fabrication of intra-oral splints and alteration of food consistencies. MRI scanning may prove helpful in delineating intra-articular derangement requiring either open or closed procedures. The role of cineradiography or “video x-ray” remains controversial. Arthroscopy and less commonly open procedures may be used to explore the joint and remove damaged tissue. Occasionally, when discal damage is severe, artificial discs may be implanted surgically.

### **Tension Type Headache**

Tension type headache (TTH) can be divided into chronic and episodic variants. There is also a further subdivision associated with whether or not there is pericranial muscle tenderness. Episodic TTH is differentiated from chronic TTH mainly by the frequency of the attacks, with the episodic form occurring no more than 15 days per month. Recent evidence suggests that there may be two general variants of TTH, one with neurovascular or migraine type features that is fairly responsive to anti-migraine medications and the other without such features and/or drug responsiveness.

Most persons experience bilateral pain, typically vice-like and localized to the temple regions. However, up to 20% of individuals with TTH present with unilateral headache pain. Episodic TTH may respond to anti-migraine measures, both pharmacologic and non-pharmacologic. Certain other pharmacologic interventions also have been found to be potentially helpful with both episodic and chronic TTH including but not limited to: tizanidine, venlafaxine and botulinum toxin. Specialized psychological and pain management services also should be considered for such individuals. (See “pain management issues” below)

### **Neuritic and Neuralgic Pain Syndromes**

Large nerves in the scalp also may be injured following trauma, either as a result of direct injury or entrapment from muscles which have been injured and are now in a state of “spasm” (more appropriately called myodystonia). The most common large nerves involved in post-traumatic headache pain are the greater and lesser occipital nerves. However, other nerves also may be involved such as the supra- and infraorbital nerves. Sometimes, one may see headache pain generated by local contusion and/or laceration to the scalp with underlying damage to scalp nerves. This type of pain tends to be a shooting, stabbing type pain.

Greater occipital neuralgia has a very classic physical exam finding of tenderness over the greater occipital nerve with referred pain into the front and side (i.e., frontotemporal region) of the head, sometimes with associated pain around or behind the eye. The only way to make this diagnosis is to palpate thoroughly the soft tissue of the craniocervical junction. Unfortunately, this aspect of the “headache exam” often is neglected. Neuritic and neuralgic pain syndromes of the scalp/head may be treated in several ways including: (1) consideration of local nerve blocks, (2) treating associated muscle spasm, (3) counter-irritation techniques, (4) use of topical medication such as

capsaicin or other “compounded” topicals for pain mediated by small nerves in the scalp and (5) cryoanalgesia. The last and most aggressive treatment would be surgical intervention.

### **Cervical Sympathetic Nerve Syndromes**

Certain nerve fibers in the front and back of the neck may be damaged from excessive flexion or extension of the neck associated with cervical acceleration/deceleration injury. Anterior injury may produce a variety of clinical conditions including so-called dysautonomic cephalalgia (pain in the head). Such injury may result in partial or total nerve dysfunction which impacts on how the condition is treated relative to medication choices (i.e., tricyclic antidepressants or beta-blockers). Involvement of posterior cervical sympathetic dysfunction (also known as Barre-Lieou Syndrome) may produce symptoms of pain in the back of the head, tinnitus (buzzing in the ears), blurry vision and vertigo. Symptoms will be similar to conditions limiting blood flow to the posterior part of the brain. Treatment mainly is directed at mobilization, control of inflammation and pain management.

### **Neurovascular or Migraine Headache**

Post-traumatic neurovascular headache or migraine accounts for up to 20% of chronic post-traumatic headache. It generally is treated similarly to nontraumatic migraine. Neurovascular headache treatment should include looking at all associated factors that may influence the headache picture, including reduction of so-called trigger factors that may include physical and/or psychoemotional stressors and—less commonly—certain types of food.

Treatment should be directed at minimizing the functional disability associated with the headache through both pharmacologic and non-pharmacologic interventions. Appropriate medication prescription should consider the use of abortive, symptomatic and/or prophylactic agents. A small percentage of women who take birth control pills may be exacerbating their migraines and this should be considered in the overall holistic treatment of individuals with post-traumatic migraine. Other interventions such as relaxation training and biofeedback also should be considered. Newer techniques including the use of botulinum toxin injection into pericranial musculature also should be considered. Although an off-label use of the drug, it has been found to be quite effective in modulating neurovascular headache symptoms.

Although arguably a poor term, chronic daily headache (CDH) should be recognized when it is present. CDH may be subdivided into: transformational migraine, chronic tension type headache, new daily persistent headache and hemicrania continua. Additionally, it is important for clinicians to be aware of other migraine-like headaches including drug-induced headache, exertional headache, “sexual headache” and rebound/withdrawal headache. There are some atypical variants of post-traumatic migraine such as basilar artery migraine (BAM) that may occur more frequently in young females, particularly following “whiplash” injury. The exact reason for this still is unclear. If unresponsive to more traditional migraine medications, this type of vascular headache—also known as basilar migraine—can be treated with anti-seizure medications such as carbamazepine. Other less common migraine variants following trauma may include ophthalmoplegic, hemiplegic and confusional migraine. An interesting type of migraine variant that may be seen in children is transient cortical blindness which, as implied by the name, is temporary and generally benign in nature.

### **Rare Causes of Post-Traumatic Headache**

There are multiple rare causes of headache that also should be considered posttrauma such as: tension pneumocephalus, carotid cavernous fistulas, late extraaxial collections (including subdural and epidural hematomas as well as subdural hygromas) cluster headache, “over-” and “under-shunting” and communicating hydrocephalus. Appropriate neurodiagnostic tests such as

CT or MRI scanning of the brain, X-rays, angiography or magnetic resonance angiography (MRA) and other vascular studies should be conducted as necessary by the treating clinician to rule-out such disorders.

### **Pain Management Issues**

Due to the nature of chronic pain, your doctor may decide to treat you with a variety of techniques. Medications, various physical modalities, injection techniques, psychological therapies, pain adaptation counseling and pain cope groups are among the variety of possible interventions. It is quite common that persons with chronic pain develop emotional difficulties such as depression and/or anxiety that may further increase their perception of their pain and their subjective level of distress.

Many times referral to a psychologist or pain specialist may be indicated to help the person with the headache condition learn to deal better with their pain. Biofeedback, stress management and cognitive-behavioral therapies do help many persons with headache, including those without evidence of psychological problems. Such interventions should be provided by persons adept at chronic pain management and experienced with working with persons with brain injury and their families.

Education of the individual with PTHA is crucial to optimizing treatment success and decreasing distress and poor adaptation to pain, particularly when the pain is chronic. One of the most important pieces of education is making sure the person understands their disease process and the expectations of treatment. Another very important area is making sure the individual comprehends how to take their medication and the potential detrimental effects of non-compliance and/or over-use (i.e., drug induced headache and/or rebound headache). Pain associated with PTHA can interfere with thinking in terms of decreased attention and concentration with perceived memory problems. Such interference often can produce false positive diagnoses of mild TBI in persons following cranial or cervical trauma with significant PTHA. Pain also can disrupt sleep and behavior. Many individuals with significant acute and chronic pain syndromes note increased irritability and a “shorter fuse.” With appropriate management of PTHA and pain in general, the aforementioned conditions generally can be modulated, if not eliminated. However, if pain management interventions are to be optimally effective, it is crucial to address the adaptational and behavioral concomitants to pain.

### **Conclusions**

Multiple studies—some completed only in the last three to five years— demonstrate that ongoing litigation has little to no effect on the persistence of headache complaints. Specifically, studies have shown that individuals still continue to report significant symptoms even after litigation has ended. A very small population will develop intractable post-traumatic headache. In this practitioner’s experience, when properly treated, most PTHA is not permanent and/or “totally disabling” over the long-term.

With the appropriate time taken in acquiring an adequate pre- and post-injury history, as well as conducting a careful clinical evaluation and ordering appropriate further diagnostic testing, the experienced clinician should be able to determine the underlying cause for the post-traumatic headache condition. Once the appropriate diagnosis is made, treatment should be instituted in a holistic fashion with a sensitivity to maximizing the benefit/risk ratio of any particular intervention and/or prescribing treatment that optimally can be complied with educating the person and family regarding the condition, its treatment and prognosis.

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- If interested in a more comprehensive listing of references regarding posttraumatic headache, call the Brain Injury Association at (800) 444-6443.

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6. Mapping the Way: Drug Therapy and Brain Injury
7. Traveling Toward Relief: Dealing with Spasticity and Brain Injury
8. Journey Toward Understanding: Concussion and Mild Brain Injury



# **The Road to Rehabilitation**

## **Part 3: Guideposts to Recognition: Cognition, Memory & Brain Injury**

Written by Joseph Bleiberg, PhD

Content reviewed by Gregory O'Shanick, MD  
Medical Director, Brain Injury Association of America

**Brain Injury Association of America**  
**The Voice of Brain Injury.**

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## **Introduction**

### **Cognition and Memory Defined**

The dictionary definition of cognition is “the mental process or faculty of knowing, including aspects such as awareness, perception, reasoning, language, memory and judgment.” Thus, cognition includes all of the brain’s mental input and output, from basic activities like using language and arithmetic during a trip to the grocery store, to complex decisions like selecting between two job offers, to the creativity of writing a poem or song, to being able to understand things from another person’s perspective and maintain an emotionally intimate relationship with them.

Part of cognition, memory is much more than simply a passive storage system for knowledge. Memory is a set of active processes that encode information. Memory “packages” the information so that it is easier to remember and can be associated with related items already in memory. Memory also involves storing information, which includes constantly re-arranging what has been stored so that new knowledge is integrated with what is already in storage, and locating and retrieving information as it is needed. For example, cognition assists memory by helping to identify what is important to remember, thereby freeing you of having to recall everything.

A few types of brain injury, such as viral infections deep within the brain, can impair memory without affecting other aspects of cognition. However, in the vast majority of cases, memory impairment is part of a larger cognitive impairment. In fact, many symptoms of brain injury that appear to be memory problems on the surface really are secondary consequences of cognitive deficits. For example, impaired attention and concentration can reduce the amount of information a person takes in, such that even if they have perfect memory, only a portion of the original information will be remembered.

### **Effects of Brain Injury on Cognition**

The brain is a person’s organ for thought, emotion and behavior. Injury can disrupt any or all of these brain functions, including the brain’s ability to integrate functions and produce complex behavior. As you are reading this pamphlet, you are using your perceptual abilities to see the printed page, your language abilities to make sense of what you see, your memory encoding and storage so that some of what you read will remain with you afterwards, your concentration to keep all the things going on around you (and inside you) from distracting you, your capacity to form intentions and plans—so that it was you who decided to do this at this time—and your mental flexibility, so that if you smell smoke or hear a baby crying you can re-prioritize your plans and stop reading in order to do something that is more urgent.

Therefore, in asking, “*What types of cognitive impairments are associated with brain injury?*” The answer is that everything a human being does can be affected by brain injury. While everything can be influenced by brain injury, different diseases and injuries to the brain certainly do produce their own characteristic sets of symptoms. Keep in

mind, however, that even though the disease/injury process (i.e., stroke, traumatic brain injury, anoxia, infection, tumor) and the area of the brain that is involved may be known, the ability to predict the types of cognitive and behavioral problems that will result is good, but by no means perfect. The only way to identify reliably the specific impairments of any given person with brain injury is through careful interview and examination of that person and—equally as important— through detailed interviews with the person’s loved ones and care providers.

### **About Terminology**

Making sense of all the technical terms for cognition is no easy task. There are hundreds of terms for specific components of cognition, and it is hard for anyone to keep track of them. There are many items that have the same or very similar meanings. Even worse, there are times when the same term means different things to various professionals using it. Some of these differences reflect important scientific and theoretical nuances, but others merely are professional jargon, so called “cogno-babble.” Whatever the reason for becoming confused by technical terms, your best approach simply is to go beyond the term by asking the professional to give you an example grounded in real-life behavior. Thus, if you read a report or are told “Mr. X has deficits in alternating and divided attention, combined with impaired metacognition,” you can ask and be told “Mr. X has difficulty keeping track of more than one thing at a time, and he does not observe himself to gauge how well he is doing, so he also is unaware of his problem.”

### **Cognitive Functions**

The most useful way to understand the cognitive consequences of brain injury is to know some of the basic categories of cognitive function:

#### **Mental Power**

This is the basic, raw energy that supports mental activity. It refers to how much mental work can be performed per unit of time. There is no “good” or “bad” mental power. Rather, power can be used to sustain something simple (i.e., operating a flashlight) or something complex (i.e., operating a personal computer). In both cases, the main issue centers on having enough power on hand. In the cognitive realm, power refers to arousal level (coma being an example of not enough power), to concentration span, to “channel capacity” (how many lines of thought-channels a person can manage simultaneously) and mental stamina.

Power is an important concept in brain injury. The brain areas involved in generating and regulating mental power are very vulnerable to injury, and the majority of persons with moderate to severe brain injury have some impairment in this area. Early on in recovery, the impairments usually are obvious, with the individual with brain injury having difficulty staying awake or focusing his/her thoughts. Months or years later, the residual symptoms may be very subtle, such as the individual having strong mental energy most of the time but showing deficiencies after too little sleep, having a cold or being under stress.

#### **Specific Cognitive Abilities**

This refers to a person's stored fund of skills, abilities and knowledge and includes items such as: reading, writing, language comprehension, motor skills and visual-spatial skills. The brain areas that control these functions very frequently are affected by strokes but less often are affected by brain injury. Indeed, when a person with brain injury complains of difficulty in these areas, for example in reading, it is important to assess whether the problem is in the actual skill of reading or whether there is a mental power problem such as poor concentration that is preventing the person from using reading to accomplish a desired result.

### **Executive Abilities**

This is a very large category of cognitive functions and includes abilities such as: anticipating future needs and planning accordingly, setting priorities, regulating impulses and drives, self-awareness and self-correction. In essence, these are the capacities which allow a person to use his/her mental power and specific cognitive abilities to meet social, vocational and internal psychological needs. Imagine you are at a computer that has state-of-the-art software (specific cognitive abilities), a fast processor and lots of memory (mental power); you still need executive abilities to decide what to do, when to do it and what to do first. Further, you must use your executive abilities to decide if you have done well enough to go on to the next task, or if it is okay to play a game on the computer.

The primary cause of impaired executive functions is frontal lobe injury, which is frequent and caused by bruising and/or bleeding in this region of the brain. A number of persons with brain injury have good recovery of their mental power and specific abilities but may be left with executive deficits which limit their capacity to assemble such intact abilities into useful "packages" of behavior.

For example, a person with brain injury returned to the rehabilitation hospital for a social visit and was observed on the elevator assisting a person using a wheelchair to get off the elevator. Motor skills, balance and coordination all showed dramatic improvement since discharge, and the person showed excellent visual-spatial skills in manipulating the wheelchair in a crowded elevator. The problem was that the person in the wheelchair had not been asked if this was the floor he wanted nor was he asked if he wanted help. The help was done skillfully and with vigor, but the results were poor.

The main point of the above discussion is that, in many cases, complaints such as "I can't remember things" or "I can't read anymore" are due to impairments in executive function or mental power. Identifying the underlying cause of a complaint is important because it increases the precision with which we can target therapy.

### **Cognition and Personality**

Cognitive impairments also can affect personality and emotion. For example, having a considerate and empathetic personality requires the ability to think about someone else's needs, feelings and desires and—at the same time—think and experience one's own needs, feelings and desires. Consider a generous, considerate and empathetic person who sustains a brain injury and is left with a deficit in the ability to manage two lines of

thought at the same time. This person may appear to have become selfish and self-centered when, in fact, he/she may retain their former considerate personality but not have the cognitive ability to implement their intentions. If you point out an instance of selfishness to the person in the above example, he/she may experience remorse and guilt and truly be puzzled about why they are behaving in ways so uncharacteristic of them.

The experience of having cognitive impairment in itself is frightening and discouraging and often leads to depression and anxiety. While such reactions can be a source of great pain and despair for the person and his/her loved ones, it is important to keep in mind that they also are positive signs, indicating that the person now has the cognitive ability to be aware of his/her situation. A common scenario is for the person to be in a good mood early in recovery when self-awareness still is very impaired; and then as self-awareness improves, the individual enters a phase of depression. A competent cognitive treatment program will pay close attention to such emotional issues and will have the capacity to provide psychological and psychiatric treatment as needed.

### **Course of Cognitive Deficits**

In most cases, cognitive deficits are most severe immediately following injury and show an improving course thereafter. A commonly used rule of thumb is that recovery is rapid in the six months to one year after emerging from coma, and that it continues at a slower pace for the next one to three years. However, there are many exceptions; not everyone's course of recovery runs smoothly or follows this pattern.

Sometimes, one cognitive deficit can hide other cognitive deficits, and it is not until the first deficiency improves that the other deficits can be seen. For example, impaired alertness and mental power can result in a person being lethargic and not exhibiting much behavior. As mental stamina improves, the amount of behavior also increases. For the first time, it becomes possible to see that the person has problems with impulse control and logical reasoning. This can be discouraging particularly to individuals most emotionally involved.

Another factor that influences the course of cognitive impairment is the person's environment. Often, families will note that their loved one's cognitive deficits "worsened" upon leaving the hospital. Usually, there has been no real deterioration. Rather, the hospital was a simple environment where a person was told what to do, when to do it, when to stop doing it, what he/she was doing well and what needed improvement. A person with impaired executive abilities can function quite well in such a hospital environment. At home, the person wakes up the next morning and has severe problems simply deciding what to do next. Thus, cognitive deficits can be hidden by simple and supportive environments, and later unmasked by complex and challenging environments

Finally, when a person is showing an unstable, flat or negative course of cognitive recovery and it is not caused by identifiable factors such as those just mentioned, medical complications should be suspected and evaluated.

### **Assessment and Diagnosis of Cognitive Deficits**

Assessment serves many purposes. It is used to: (1) identify areas of cognitive impairment and cognitive strength, (2) monitor improvement or deterioration, (3) design remediation programs, (4) evaluate the outcomes of treatments, (5) predict future vocational and educational capacity and (6) document symptoms for legal, insurance and educational issues, as well as for purposes of public benefit eligibility (i.e., Medicaid and Social Security).

During the recovery process, cognitive deficits not only change in severity but—as noted previously—different impairments may appear as others disappear. This means that the person’s status cannot be captured by any single assessment. Instead, many assessments must be conducted throughout the recovery period to capture the dynamic nature of improvement.

### **Timing of Assessment**

Early on in recovery, individuals typically are confused, disoriented, agitated and impulsive. Conversely, in some cases, individuals may be lethargic, apathetic, somnolent and uninterested. During this phase, it is pointless to engage in detailed, lengthy and expensive cognitive assessments. Deficits such as agitation or apathy prevent a person with brain injury from participating meaningfully and reliably in these evaluations. Moreover, at this phase, people often change so rapidly that the results of the assessment can be outdated by the time the report appears on a medical chart. Most useful at this stage are simple and brief rating scales of amnesia, orientation and behavior. Legal needs for careful documentation of status can be met via these rating scales and by videotaping the person.

After brain injury, most individuals recover sufficiently to participate meaningfully in cognitive assessment. Once at this stage, it is possible to begin identifying the specific cognitive abilities that are damaged, as well as those that are intact. Identifying cognitive strengths is just as important as finding the deficits, as it is the areas of strength that will be the foundation of recovery.

At this point, the future legal needs of the person with brain injury also should be considered. Cognitive assessment provides information useful for guardianship and competency decisions and for documenting eligibility for disability insurance and other compensation. If legal proceedings are anticipated, it is very important that at least one of the assessments use formal, standardized neuropsychological tests that have a known record of acceptance by the courts. Keep in mind that the legal proceedings may not take place for many years, by which time the person with brain injury can look dramatically better but still have deficits which are difficult to measure. It is much easier to make a convincing argument that such subtle deficits are due to the brain injury if there is data demonstrating that the same deficits were present in a not so subtle form at an earlier time.

Individuals in professions which offer treatment for cognitive impairments (i.e., neuropsychology, occupational therapy and speech and language pathology) use tests specially designed to identify cognitive deficits, and incorporate this information into the treatment planning process. However, tests are only part of a good assessment. Equally important is measurement of the person's real-life functioning (i.e., "He has a great IQ, but can he tie his shoelaces?"), which includes the observations and perceptions of family members and caregivers.

The functional assessment especially is important for identifying impairments in executive functions (i.e., "If left alone, does he tie his shoelaces?"). The evaluation also should include learning as much as possible about the person's pre-injury level of function. School records, work samples and test scores from before the injury help therapists to identify what is "normal" for that particular person.

The cognitive assessment always should be paired with an assessment of the emotional state and the reactions to how brain injury has affected the person's life, including hopes, dreams and aspirations. If left untreated, emotional reactions can develop into full blown psychological disorders that may become as disabling as the cognitive deficits. Moreover, depression and anxiety by themselves can degrade cognitive performance.

### **Recovery**

The mechanisms underlying recovery of cognitive function are not understood completely. It is known that for weeks and possibly months after injury there is actual healing occurring within the brain. Nerve cells that have died do not heal or regenerate, but injured nerve cells can heal and return to active function. Also, some of the generalized effects of injury, such as swelling, gradually subside and permit surviving nerve cells to resume functioning. In addition to healing, there probably is a component of the brain reorganizing its circuits so that the remaining healthy nerve cells take over some of the functions of the damaged cells, a process termed *reorganization of function*. Along with biological mechanisms of recovery, there are behavioral and cognitive mechanisms which fall into two categories—*learning* and *compensation*. Damaged nervous systems are capable of learning new behaviors. The learning may be slower post-injury, less complete and with a higher error rate, but there is no question that some capacity for new learning remains, in most cases. However, the new learning may take many years of recovery, long after the biological healing processes are over.

Compensation refers to techniques where assistive devices or procedures are used to overcome impairments that cannot be modified. For example, a wheelchair is a compensatory device. In a case in which exercises will not result in a person's being able to walk, the wheelchair provides mobility. These assistive techniques take many forms. For example, compensatory environments are settings where complexity, novelty or supervision intensity are controlled so as not to exceed the person's cognitive capacity. The degree to which performance can be enhanced by a supportively-structured environment is remarkable. Helpful devices exist that help a person perform cognitive

functions, such as memory logbooks, electronic watches that emit a signal for the person to perform some activity that they would not remember (i.e., taking scheduled doses of medicine) and computer software that can assist a person to organize and manage complex information.

## **Treatment**

Treatment of cognitive disorders takes several forms, depending upon the problem:

### **Mental Power**

Problems such as poor mental stamina or poor concentration often respond well to fatigue management strategies. The person's sleep-wake cycle is analyzed to determine if daytime alertness can be improved. Many persons with brain injury have disturbed sleep-wake cycles, and some have true sleep disorders. Such disturbances can be corrected by behavioral therapies to improve sleep hygiene and remove impediments to sleep. Medical treatments also may be helpful. In some cases, the treatment is as simple as scheduling a brief nap. In addition, fatigue management includes working with the person to find the optimum balance between work and rest. Overwork or exceeding one's limits may backfire badly in someone who has problems with mental stamina. It may take many days to restore a person to the former level of function.

Problems with alertness, attention and concentration also can be treated medically. The use of medicines to improve cognitive function following brain injury is relatively new, but there is no longer any question that some persons obtain meaningful benefit. It is best to identify a physician experienced in this area and then work closely with him/her.

### **Specific Cognitive Abilities**

Impairment-specific interventions focus directly on the area of deficit, such as when an individual has memory problems and is given memory training. Impairment-specific interventions for speech/language problems, visual-spatial abilities and attention have shown some record of success. However, memory training has shown mostly disappointing results, in contrast to memory treatments based on compensatory devices such as logbooks, which have shown good success.

### **Executive Deficits**

Executive deficits are best treated through programs that utilize real-life performance as the treatment focus. The person with brain injury may be observed within the community or work setting and therapy occurs as the person is performing. An example of this is job-coaching. In this situation, the person takes a job and the therapist attends the job site and assists and trains as needed. Executive deficits also can be treated in individual therapy, though this is usually in addition to and not instead of treatment in real-life situations.

Comprehensive brain injury rehabilitation programs provide integrated treatment of all three categories of deficits. The mission of these programs is that of helping the person with brain injury repair his/her overall level of function and quality of life. Such treatment has a broad focus that includes: (1) interpersonal and social skills, (2) work and school behaviors such as completing assignments and being punctual, (3) emotional

adjustment and self-acceptance and (4) using cognitive skills in real-life settings. Most studies of comprehensive programs have shown moderately positive results, though even the most successful programs do not help everyone.

Rehabilitation clinicians frequently encounter requests from persons with brain injury and their loved ones for more treatment on the assumption that if a given amount of treatment is good, then more would be better. Very often, this is not correct. In many cases, the most important factor is that a reasonable amount of treatment be provided for a very long time. Because of the need for long periods of treatment, it is important to maintain motivation and interest and not burn everyone out by a heroic sprint. Recovery from brain injury is a long distance run.

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## 8. Journey Toward Understanding: Concussion and Mild Brain Injury



## **The Road to Rehabilitation Part 4**

### **Navigating The Curves: Behavior Changes & Brain Injury**

Written by Terry J. Page, PhD

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The Voice of Brain Injury. [www.biausa.org](http://www.biausa.org)

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## Introduction

Individuals who have sustained a brain injury can face many difficult challenges. Some people have physical disabilities, such as paralysis or loss of a limb. Many individuals have emotional problems, such as depression or mood swings. Most persons must overcome cognitive problems, such as memory loss, difficulty with problem-solving and/or decision-making. Often, behavior problems can be a difficult hurdle—for individuals—as well as their families and friends.

Behavior challenges can appear in many forms. Problems with social skills and interactions with other people account for the most frequent behavior problems. Unfortunately, other more severe behavior problems also can appear following brain injury. Aggression toward others, self-injury, property destruction, tantrums, yelling, cursing and noncompliance can cause serious concerns for families, friends, teachers, co-workers and others. At the very least, these behaviors can be annoying and troubling. At worst, such behaviors can cause serious injury or property damage. Perhaps most importantly, behavior problems can interfere with rehabilitation. They also can be an obstacle to community reintegration. The following material will offer advice on ways to identify behavior problems and to deal with them effectively, helping you and your family move toward recovery.

Behavior problems are the least understood of all problems faced by individuals recovering from brain injury. Unlike the fields of medicine, physical therapy and other forms of treatment, the approach to treating behavior problems is not always based on agreed upon principles. Professionals from many disciplines in the field of brain injury rehabilitation attempt to understand and treat behavior problems. These professionals include behavior analysts, cognitive therapists, neurologists, neuropsychologists, nurses, occupational therapists, physiatrists, psychiatrists, psychologists, recreation therapists, rehabilitation counselors and speech pathologists. Each works to assess the individual's strengths and the ways in which behavior problems interfere with independent functioning. Likewise, each is involved in attempting to decrease maladaptive behaviors and teach more adaptive skills.

Approaches can vary greatly because professionals in contrasting disciplines receive different types of training. Even the field of psychology contains many different schools of thought, many with differing theories. Treatment approaches based on one theory can vary in fundamental ways from treatment approaches based on a different theory.

Some psychologists believe that changing the way people feel about themselves and their behavior will result in behavior problems not occurring. Others recommend giving individuals an opportunity to discuss their problems and how they might relate to childhood experiences. Still other professionals feel that the best method of treating behavior problems is to place the individual in a positive and supportive environment.

There are no simple universal solutions to treating behavior problems. Every person with behavior problems is an individual whose situation is unique. Still, certain approaches to treatment have proven effective and should be included in most treatment approaches. This booklet will help you better understand behavior problems and find effective treatment.

## **Defining Behavior Problems**

Basically, behavior problems are acts that either are dangerous or have a negative effect on an individual's rehabilitation or community reintegration. But, it is not easy to sum up what constitutes a behavior problem. Behavior problems are determined by the community and the specific situation in which the behavior occurs. Many behaviors are acceptable in some situations, but not in others. For example, fighting is encouraged in defense of one's country and in the boxing ring. However, fighting becomes a problem when it occurs in the home or the workplace. Yelling is acceptable at sporting events, but not when interacting with family members. Property destruction is expected when someone is hired to tear down a house, but presents a problem in a rehabilitation facility or someone's home.

Many individuals have occasional inappropriate behaviors that are not dangerous and do not impede their rehabilitation or their ability to function. The best way to identify a behavior problem is to consider an action's severity and how often it occurs.

### **Severity**

Severity of a behavior is determined by its impact on other individuals in the immediate vicinity. For instance, mild aggression, in the form of hitting, may not be considered a behavior problem by family or rehabilitation professionals. But more severe aggression, such as hard punching, biting or tearing clothes, is unacceptable in most situations. Likewise, a mild temper tantrum might be acceptable, whereas a serious outburst with loud yelling and major property destruction cannot be tolerated in most situations. In cases of severe problems, the behaviors must be treated so that the individual can make maximum progress toward rehabilitation goals.

### **Frequency**

Some actions can constitute behavior problems because of their extreme frequency. Making inappropriate statements to others may be acceptable if it does not occur too often. However, if such comments are made repeatedly—possibly hundreds of times per day—they may interfere with rehabilitation or community reintegration. Similarly, mild aggression or self-injury might be acceptable on a once-a-week basis. But, if it occurs repeatedly every day, it is easy to see how such behavior might interfere with rehabilitation or community reintegration. As with more severe behaviors, problems that occur frequently must be treated for an individual to realize progress in his/her rehabilitation goals.

## **Causes of Behavior Problems**

Human behavior is very complex. What people do, why they do it and how they do it has been the object of scientific study for centuries. In this brochure, what is known about behavior as it relates to individuals who are recovering from brain injury will be discussed. There are two factors that determine our behavior: the brain and the environment. When either is affected, a person's behavior can change. Unfortunately, some changes in the brain and the environment have the unwanted effect of producing inappropriate behaviors.

### **Neurologic Causes**

The brain controls our thought processes and all bodily functions. In short, it controls behavior. When the brain is injured, behavior often is affected. Unfortunately, many changes in behavior following brain injury are not adaptive or acceptable to other people. Such behavior can take many forms, as illustrated by the examples below.

Many people experience increased agitation for a period of days, weeks or months following brain injury. This agitated state is a natural result of the damage to the brain and the disruptive effect that it has on a person's general functioning. In many cases, the agitation goes away as the brain learns to function in its newly acquired injured condition. But in some cases, agitation can be a lifelong condition that results in significant behavior problems if not treated.

Damage to the frontal lobe, common in motor vehicle crashes and assaults, can cause specific behavior problems. The frontal lobe controls decision-making, judgment and other executive functions. Often when the frontal lobe is damaged, an individual has great difficulty tolerating frustration or overstimulation. This can lead to feelings of agitation and, sometimes, to yelling, cursing, aggression, property destruction and/or other such behaviors.

In many types of brain injury, a person has difficulty with concentration and judgment, as well as problem-solving, making decisions and understanding subtle environmental cues. In turn, the person may become confused, make a bad decision or act impulsively, leading to acting out behaviors such as aggression or property destruction.

In many cases, behavior problems are the result of impaired ability to process information or understand situations accurately. Behavior problems also can occur because individuals often become fatigued easily following a brain injury. Brain injury can affect memory, vision, hearing and communication in ways that increase the probability of behavior problems. Another source of unwanted behaviors can be emotional responses related to damage to the limbic system.

Thus, it is easy to see how damage to one's brain can lead to behavior problems. These problems can be traced to the neurologic damage and the impaired interactions that follow, and are in no way the fault of the individual.

## **Environmental Causes**

An individual's environment consists of everyone with whom he/she comes in contact with and everything that happens to him/her. The environment's responses to behaviors profoundly affect how people act. There are four primary ways in which the environment affects how we behave:

**Responding to Cues:** Everyone behaves by responding to cues from the environment. Questions from others, instructions and written signs all exert control over behavior. Successful people learn to make appropriate decisions and responses to cues from the environment. For example, a stop sign or a red traffic light provides cues that it is appropriate to brake a moving vehicle. Instructions to complete a certain task provide cues about what is expected by someone else.

**Positive Reinforcement:** When good things happen to a person following some behavior on his/her part, the individual is more likely to repeat that behavior in the future. For example, if people are thankful and smile when someone holds the door for them, the person will be more likely to hold doors for other people. However, if a person never received positive feedback for holding a door, they eventually would stop holding doors for other people.

**Negative Reinforcement:** When behavior gets a person out of unpleasant situations, or if it removes the threat of one, that behavior becomes strengthened. Again, it is more likely to occur in the future. For example, suppose a young child asks his/her parent for candy while at the grocery store. The parent tells the child that it almost is time for dinner. The child begins to cry and scream. This causes everyone in the store to look at them, which makes the parent very uncomfortable. So, the parent gives in to the child and buys the candy. This causes the temper tantrum to stop, and everyone stops looking at them. The parent's action of giving in to escape from the unwanted attention has just been strengthened, and will be more likely to occur again in similar situations. It has been reinforced negatively by removal of the unpleasant situation.

**Punishment:** When an individual's behavior leads to a negative consequence, they are less likely to exhibit that behavior again. For instance, if people frowned and hushed a person for talking in a movie theater, that person probably would stop talking. If this happened several times, the individual probably would think twice before talking in a theater again. In these four ways, our environment influences the development of acceptable behaviors as well as inappropriate behaviors. These factors can be used in therapy to help individuals change their behavior and learn appropriate, adaptive behaviors. Additionally, the environment can contribute to the development and persistence of behavior problems in a number of ways related to the four environmental factors discussed above:

**Responding to Cues:** Following damage to the brain, a person no longer may be able to respond to customary cues as he/she once did because he/she does not notice, understand or process cues quickly enough. What previously had been a cue to do a simple chore may be misunderstood as a hostile or demeaning threat. Or, an individual may have

trouble keeping up with family or friends in terms of responding to social cues from others, and may express his/her frustration with aggression or withdrawal.

**Positive Reinforcement:** It has been documented scientifically that behavior problems sometimes are maintained because they result in attention from other people, such as family, friends, staff or other clients. Consider someone who experiences cognitive difficulties that lead to depression, confusion and self-doubt about the future. In addition, this person occasionally has episodes of aggression accompanied by property destruction. During the outbursts, he becomes the center of attention for therapists and other staff who are present. Following the outbursts, he has individual meetings with a therapist, a counselor, a neuropsychologist and the residential director to discuss what happened. The attention from other people is comforting, and lets this person know that others care about him. Plus, the fact he gets to meet with staff on a one-on-one basis is helpful and reassuring. This type of positive attention strengthens the inappropriate behavior that preceded it.

Likewise, people learn that an inappropriate behavior, such as a tantrum, can result in access to preferred activities, such as watching a favorite TV show, staying up late or gaining access to snacks or other preferred items.

In many cases, the response to inappropriate behavior can include an element of reprimanding. Still, research has shown that even severe behavior problems such as aggression and life-threatening self-injury can be maintained by the positive reinforcement of another person's response.

**Negative Reinforcement:** Despite the best intentions of skilled and caring rehabilitation professionals, the recovery process can be very unpleasant for individuals who have sustained a brain injury. Physical activities can be painful. Seemingly simple cognitive activities can be confusing and difficult to perform. Speech problems may make it difficult to speak, or to be understood. Many activities may seem childlike and become demeaning or embarrassing.

It is easy to see that individuals undergoing rehabilitation or attempting community reintegration often are confronted with situations that are unpleasant for any number of reasons. Sometimes, individuals learn that they can use inappropriate behavior to avoid unpleasant situations.

Consider someone who finds physical therapy painful and frustrating. The individual may learn that attacking his/her physical therapist or the orderly transporting him/her to physical therapy results in the person being rescheduled for some easier therapy or being allowed to do nothing. When this happens, the inappropriate behavior is strengthened by avoidance of the unpleasant situation. Similarly, a person may not like occupational therapy because he/she cannot complete the cognitive exercises and feels like a failure. Or, the individual may not like the therapist or other group members. In some cases, this person will learn that if he/she has an outburst that disrupts the session or scares others, he/she may be excused from therapy. In this case, the outburst will be reinforced by the

escape from therapy, making it more likely to occur in the future.

**Punishment:** Behaviors that are followed by unpleasant consequences are less likely to occur in the future. Unfortunately, this can complicate the rehabilitation process, where necessary measures result in unpleasant consequences such as pain, confusion, embarrassment or failure. A person's efforts to participate in rehabilitation can be discouraged in this way. For example, when a person unsuccessfully attempts to master a previously known skill such as walking or talking, failure and the associated frustration and embarrassment can be discouraging to future attempts.

Most people have learned that they do some things well and have trouble with other things. The same is true for the person undergoing rehabilitation or community reintegration. When the skills that are most important to a person's recovery are followed by some type of punishment, those behaviors are weakened. Then, a person's ability to obtain positive reinforcement is limited. As a result, the individual is prone to find other behaviors that are effective, even if those behaviors sometimes are inappropriate. Other individuals may withdraw into depression and social isolation as they experience more and more failure.

It should be stressed here that as with neurologic causes, behavior problems caused by environmental factors are not the fault of the individual who has sustained brain injury. The fault lies in the environment accidentally strengthening inappropriate behaviors instead of appropriate responses. Unfortunately, the rehabilitation environment itself often is responsible for reinforcing behavior problems. This can happen when cues are confusing or unclear, or when consequences for behavior problems accidentally reward the individual. It is very likely that the individual is not aware of the reasons for the occurrence of behavior problems and probably wishes he/she could behave more acceptably. Thus, the focus of treatment needs to be on changing the environment, not changing the person.

### **Combination of Causes**

For most people with brain injury, behavior problems result from a combination of neurologic and environmental causes. In most cases, the initial occurrence of behavior problems following brain injury largely is due to neurologic damage. Individuals who did not have behavior problems previously become aggressive, disruptive and difficult to get along with. Clearly, the brain injury caused these behavior problems.

However, as discussed above, the environment plays a part in determining the future likelihood of behavior. Even in cases where brain injury causes a behavior problem, the reaction of an individual in one's environment can have an effect on how often the behavior will occur in the future.

As was noted, an individual with frontal lobe damage becomes frustrated easily, leading to agitation and aggression. This aggression can be strengthened if it results in positive reinforcement in the form of attention, or negative reinforcement in the form of escape

from unpleasant tasks. In this case, the origin of the behavior was neurologic, but the behavior continues to occur in part because of environmental influences.

Alternately, if the same individual becomes aggressive as a result of frustration and agitation but the behavior does not result in reinforcement, the behavior would be less likely to reoccur. The behavior would be even less likely if the individual has been taught adaptive strategies to obtain attention or escape unpleasant situations.

It can be difficult to evaluate behavior problems that occur as a result of neurologic and environmental factors. Again, it is important to distinguish between the individual and the behavior. While it is possible to change an individual in the sense of teaching new skills, the treatment of behavior problems must focus on changing the environment. Neuropsychologists can be helpful in this area. They administer tests that identify problems with functioning related to damage in specific areas of the brain. These tests have been designed to identify a person's strengths and weaknesses in performing mental tasks. They also can be helpful in understanding a person's behavior problems, and which strategies may be most effective in addressing them.

## **Treatment Options**

Unfortunately, some individuals with brain injury and behavior problems find themselves being treated in facilities that are not appropriate for their problems. Historically, many persons with behavior problems were not able to be managed in rehabilitation facilities and ended up being placed in psychiatric facilities, where treatment staff were unaware of the complex issues related to brain injury and behavior problems. The result was ineffective treatment. A person with behavior problems and a brain injury has the right to effective treatment in an appropriate brain injury rehabilitation program.

Fortunately, there are now a number of different treatment options that can help individuals with behavior problems. The specific types of treatment depend on two factors. One is the individual. Each person is unique, with behavior problems that result from a particular combination of factors. Each behavior treatment plan must be tailored individually to the needs of the particular person.

The second factor is the degree of seriousness of the problem. Problems that are relatively minor—as measured by severity or frequency—often can be treated in community settings or outpatient clinics. More severe problems most likely will require treatment in an inpatient setting by trained staff. Finally, while behavioral therapy alone often is quite effective, the prudent use of medications in combination with the behavioral interventions outlined in this brochure also is appropriate in maximizing the individual's ability to recover.

### **Minor Behavior Problems**

With all behavior problems, the treatment of choice depends, in large part, on the specific behavior, how often it occurs and in what situations. However, any effective treatment program should include the components mentioned below:

**The individual with behavior problems should be included in the identification and design of the treatment plan whenever possible.**

Any treatment plan being considered should be discussed with the individual, in terms of what the problem is, why it is a problem and what will be done to address it. Not only is this fair from an ethical point of view, but it also usually increases the chances for positive outcomes because the individual is involved in the process.

**The plan should be as positive as possible.**

Families, and even some professionals, sometimes assume that the only effective means of decreasing inappropriate behavior is through the use of punishment or loss of privileges. While mild forms of punishment may sometimes be necessary for troublesome behaviors, many behavior problems can be eliminated through strictly positive means. Even if punishment techniques are necessary, they only should be used in conjunction with positive procedures.

**The plan should teach a person adaptive behaviors to take the place of the inappropriate behaviors.**

If someone aggresses to escape from household chores, part of the treatment is to prevent such an escape. However, it is just as important to teach the person acceptable ways of having more control over the requirement that they do chores, as well as acceptable ways to express frustration or anger. For example, you might provide the option of choosing what time chores will be done, the order of chores or what the consequence will be for doing, or not doing, the chores. And you might teach an acceptable means of requesting a short break, or asking for assistance or clarification.

**The plan's design should make it very likely that the individual will succeed, especially in the early stages.**

Take the example of the person who refuses to do his/her daily chores and avoids doing so by aggressing. Besides the considerations discussed above, you would want to make your initial expectations as reasonable as possible. No plan would be effective if the person was required to go from doing one chore a day to doing ten chores in order to earn reinforcement. Instead, the person might be more likely to comply if they must complete only two or three chores to earn reinforcement. Then, additional chores could be added gradually.

**The plan should be easy for the individual to understand.**

Complicated plans that attempt to do too much at one time can be confusing and make it less likely the individual will comply with requests.

**The plan must be implemented consistently.**

Everyone who implements the plan—whether family or staff—must have the same expectations, and be consistent in their interactions with the individual. Likewise, anyone who implements a plan must do it the same way every time. Abrupt changes in a plan can send mixed messages and could reinforce inappropriate behavior.

**The plan must be flexible enough to adapt to changes in the individual.**

Although spur-of-the-moment changes are not good, there is nothing wrong with thoughtful changes that are made on the basis of progress or lack of progress. It is best to make changes at times not associated with the behavior problems. For instance, sit down and discuss possible changes to the chore routine at night, not during the chore or in the middle of a temper tantrum.

**Although the requirement that plans be positive already has been stated, this aspect cannot be stressed enough.**

Praise individuals for appropriate behavior that represents progress away from problem behavior. For example, persons who get agitated in certain situations should receive acknowledgment and praise anytime they successfully control themselves in that situation.

When staff, parents or significant others talk about an individual in their presence, they only should discuss the person's successes. It is very helpful if a person overhears two people talking about something good he/she did, no matter how minor. Conversely, overhearing two people discuss some shortcoming or behavioral outburst can have very negative effects. People with behavior problems need a lot of encouragement to learn that they can control their behavior more effectively. Make sure they know that you are noticing their efforts and the results.

### **Severe Behavior Problems**

Unfortunately, many severe behavior problems cannot be treated effectively in most home, school or community settings. The design, implementation and monitoring that are necessary must be done in highly structured settings by trained and experienced staff. (See the following section)

## **Treatment Programs**

The following section is included to help families and professionals evaluate potential programs for the treatment of severe behavior problems. The available programs vary greatly in terms of their ability to offer effective programs for treating behavior problems. The information below can be used in determining how different programs compare in the services they offer.

### **Staff Experience**

**Are staff who will be working with an individual trained in brain injury?**

**Are there behavioral treatment staff who are trained and experienced in dealing with severe behavior problems?**

In programs to treat severe behavioral difficulties, the clinical team should include doctoral level behavior analysts and neuropsychologists who have experience with behavior problems.

**Are clinical staff (i.e., occupational therapists, physical therapists, speech pathologists, teachers, vocational specialists) trained in dealing with severe behavior problems?**

Behavioral treatment is most effective when all staff are involved, understand the plan and are comfortable implementing it.

**Are direct care staff trained in safe crisis management techniques?**

**Are they closely supervised in their implementation of behavioral treatment programs?**

### **Setting**

**Is the setting as homelike as possible or does it more closely resemble a psychiatric facility?**

The more natural the treatment setting, the more likely that treatment gains will carry over to life in the community after the person is discharged.

**Is the setting safe for someone who might be engaging in self-injury or major property destruction?**

**Is the setting secure? Is there any chance that a confused and agitated individual could leave the facility and be at risk from traffic or dangerous individuals?**

**Are there opportunities for functional and realistic activities?**

This means vocational opportunities for adults and educational activities for children.

**Are the activities realistic for the individual's age and functioning level?**

**Do they bear any relevance to what the individual will be doing after discharge from the facility?**

**Are there opportunities for appropriate recreational activities?**

People with behavior problems need leisure time. They also need opportunities to learn appropriate behavior in leisure situations.

### **Treatment Context**

**Is behavioral treatment carried out in all therapeutic contexts?**

**Are behavioral treatment programs implemented in occupational, physical and speech therapy, as well as the presence of behavioral staff?**

Behavior problems do not occur in a vacuum. They occur in therapy rooms, the dining room, the residence, the grocery store and many other places. Effective assessment and treatment demands that they be treated in all situations in which they occur.

**Are there opportunities for community outings?**

When behavior is manageable in community settings, individuals should be given opportunities to leave the facility and experience the outside world.

**Is treatment provided that is relevant to the important aspects of a person's overall rehabilitation?**

**Is consideration given to the individual's life situations, culture and planned discharge setting?**

### **General Treatment Issues**

**Are staff pleasant and positive in their interactions with clients?**

When individuals are not in behavioral crisis, staff should interact with them in a manner that shows respect, caring and positive concern for the person's well-being.

**When staff encounter clients in the facility do they greet them by name and ask how they are doing?**

**Do staff demonstrate an honest interest in individuals, for example, by commenting on some topic of interest to the individual?**

**Do behavioral treatment plans incorporate a strong emphasis on positive programming?**

**Are there many more rewards for appropriate behavior than there are loss of privileges or other punishments for inappropriate behavior?**

**Do behavioral treatment plans actually exist?**

Some well-meaning rehabilitation professionals think the best way to treat behavior problems is to avoid their occurrence. So, if a person became aggressive when asked to help prepare dinner, the plan would be not to ask the person to prepare dinner. This is not helpful because it does not teach the person appropriate behaviors. An effective behavior plan would be based on an analysis of why aggression was part of meal preparation. The plan would be implemented actively to reinforce appropriate participation and teach more acceptable ways of communicating than by aggression.

**Do behavioral plans incorporate each of the treatment components discussed above for minor behavior problems?**

**Do program staff utilize data to evaluate the success of treatment programs?**

Staff should not rely on subjective clinical impressions or their recollections over the past 30-day period to evaluate treatment programs. The treatment of behavior problems is difficult and complex and only should be evaluated on the basis of objective data that reflect an individual's performance. There should be evidence of data collection sheets and graphs that summarize an individual's progress.

## **Discharge Planning**

### **Is treatment planning conducted with the individual's discharge site in mind?**

For instance, a behavioral treatment program for a person scheduled to transfer to a group home might be different than one designed for a person going to a long-term residential facility.

### **Are treatment plans developed that realistically can be expected to be implemented upon discharge by family, teachers, group home staff or others who will be responsible?**

Initial treatment plans for severe behavior problems often must be very complicated and sophisticated. They only can be implemented correctly by highly trained staff. However, good treatment plans evolve to become more natural and able to be implemented by family, teachers and others who will be involved after discharge.

### **Are family or staff who will be expected to implement a program after discharge trained in the program?**

### **Are they given opportunities to practice implementing the program under controlled conditions prior to discharge?**

## **Outpatient Programs**

Many individuals with behavior problems can be treated on an outpatient basis. The main factors affecting whether inpatient or outpatient care is necessary are the frequency and severity of the individual's behavior problems, as discussed previously. It sometimes is possible to locate potential outpatient programs through referrals from hospital staff or professionals who provide discharge planning at rehabilitation facilities. If these sources do not prove helpful, contact either the Brain Injury Association national office or your chartered state affiliate. Either of these organizations will provide a list of possible programs.

## **Summary**

Clearly, individuals with brain injury and their families face difficult challenges. However, with a combination of support from loved ones and the right professional help, people with brain injury can maximize their level of independence and lead happy, productive and fulfilling lives.

It never is pleasant to be around someone who is displaying behavior problems. However, sometimes it is helpful to remember why the behavior problems are occurring. Behavior problems are not the fault of the individual. Rather, behavior problems occur as a result of neurological factors and the influence of the environment.

The good news is that problems can be understood and managed. Individuals respond favorably to positive changes in their environment. Today, there are thousands of individuals who have overcome behavior problems—even severe ones—and are leading productive lives. Unfortunately, treatment often is not effective immediately. Sometimes weeks, months or even years are required to achieve control over behavior problems. During and after the treatment process, the person with behavior problems needs love, understanding and patience from family and friends.

### **About the Author...**

Terry J. Page, PhD, Executive Vice President of Clinical Services and Brain Injury at Bancroft NeuroHealth, Inc., currently is responsible for overseeing rehabilitation and brain injury programs at Bancroft NeuroHealth, Inc. These programs offer a continuum of services from neurobehavioral stabilization to community-based supported living. Dr. Page received a doctoral degree in psychology from Western Michigan University. He served as a faculty member in psychiatry at the Johns Hopkins University School of Medicine for nine years, where he directed an inpatient treatment unit for severe behavior problems. Dr. Page also has worked in special education classrooms, developmental disability centers, brain injury rehabilitation programs and community-based residential facilities. His research activities have included assessment and treatment of severe behavior problems, teaching community survival skills, staff training and management and feeding disorders. Dr. Page actively writes, consults and conducts workshops in these areas, as well as other applications of behavior analysis. He has published in and served on the editorial boards of several journals.

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## **The Road to Rehabilitation Part 5**

### **Crossing the Communication Bridge: Speech, Language & Brain Injury**

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## **Introduction**

### **Communication Problems Following Brain Injury**

One of the consequences of brain injury can be the inability to communicate adequately. Individuals can experience difficulty with speech, language and cognitive-communicative abilities that will interfere with appropriate learning and social interactions. This guide is created to assist individuals and their families understand the communication problems that can be related to brain injury and plan appropriate interventions to compensate for these communication problems. Effective planning provides individuals and their families with the most efficient means of coping with communication disorders and allows for the best interaction with service providers.

This guide presents general information about communication problems that may be experienced after brain injury. The information is presented in a question and answer format. Suggestions for how you or your family members can be involved in the rehabilitation and treatment process are presented in a series of general suggestions and guidelines.

### **Key Definitions**

**Communication:** Communication is the use of listening, speaking, reading, writing and gesturing either to understand an idea or to express a thought

**Speech:** Speech skills are different from language skills. Speech is the production of sounds that make up words and sentences.

**Language:** Language refers to the use of words and sentences to convey ideas.

**Cognitive-Communication:** Cognitive-communication skills require the ability to use language and underlying processes such as attention, memory, self-awareness, organization, problem solving and reasoning to communicate effectively.

### **How are Communication, Speech and Language Affected by Brain Injury?**

When a brain injury affects the areas of the brain responsible for: (1) producing speech, (2) understanding what is said or (3) using words to formulate sentences and convey ideas, then communication can be affected. Depending on the areas of the brain that are injured, the use of cognitive-communication skills to understand or convey information can be problematic. Any of these skills can be impaired or spared, depending on the location and severity of the injury.

Cognitive-communication skills are used to learn and function successfully in home, school, work and community life. It often is the inability to use appropriate language skills in learning and social environments that interferes with successful interactions.

Decreased communication skills sometimes lead to loss of friends, misunderstandings or poor performance in school or job tasks.

### **What Types of Speech Weaknesses Can Exist?**

Most individuals regain the ability to produce speech sounds and words after brain injury. These skills usually improve with the physical recovery of the person. When there are problems with paralysis, swallowing or other types of motor incoordination, there is a possibility that the individual will not recover the ability to speak or will have poor motor planning (apraxia) or muscle control (dysarthria) which results in unintelligible speech production. Characteristics of this type of speech may include:

- Slurred production of words
- Drooling
- Difficulty swallowing
- Hoarse or nasal voice quality
- Slowed rate of speech because of motor control difficulty, or increased rate of speech as the result of reduced self-inhibition and poor self-monitoring skill
- Total loss of the ability to use verbal speech from paralysis of the vocal mechanism

Because most people return to their pre-injury level of speech production ability, additional language and cognitive-communicative weaknesses can be overlooked.

*TIP: Speech production is only one part of a communication disorder.*

### **What Types of Language Problems Can Exist?**

There are two types of language abilities that should be considered.

**Receptive skills** are the ability to understand what is said or written. Behaviors that may indicate problems with receptive language include:

- Poor recognition of vocabulary
- Difficulty with the rate, complexity or amount of spoken or written information presented at one time
- Requests for multiple repetition of information
- Lack of attention in social conversations or teaching situations
- Problems understanding or recalling what was read

- . Difficulty remembering instructions or following directions

Additionally, persons who sustain brain injury also may have hearing loss. A decrease in hearing skills also can cause the above behaviors. A complete hearing test should be completed by a qualified audiologist to rule out hearing loss before questioning receptive language competency.

**Expressive skills** are the ability to use verbal or written skills to express an idea. As an individual recovers from the initial injury, most receptive and expressive language skills necessary for routine communication may appear close to normal. Rarely will there be a problem with formulating a sentence or understanding everyday language. The more subtle problems with language and cognitive-communication often are overlooked. Behaviors that may indicate problems with expressive language include:

- . Difficulty remembering the desired word when speaking or writing
- . Rude or immature use of language
- . Problems in developing and using new vocabulary
- . Talking about unrelated topics
- . Failure to maintain proper “social graces” in social situations
- . Making up stories or explanations for situations
- . Hyperverbal or rapid, non-stop talking
- . Lengthy, unorganized explanations
- . Retelling the same story over and over
- . Difficulty writing sentences
- . Decreased ability to spell words correctly

*TIP: Communication skills should be considered as possible contributors to problems if the person displays problems with learning, working or interacting with friends, family or co-workers.*

Standard tests for language problems often do not disclose major problems with language after a brain injury because communication problems often are more evident in functional situations than in formal test situations. Sometimes, previously learned information is recalled, test scores are inflated and individuals look better on the test than they do in actual daily functioning. Therefore, it is important for family members to report

communication behaviors they observe that seem to be causing problems for the individual.

It particularly is difficult to determine the impact of brain injury in children because they still are in the process of acquiring and refining their language skills. For example, a child may test well on a vocabulary test right after the injury because of previously learned information. However, the same child will fail to acquire new vocabulary as he/she progresses through school and will do poorly on vocabulary testing several years after the injury.

*TIP: Adequate language skills are necessary for success. Inappropriate behaviors and problems should be observed over time and considered when planning for reinvolvement in home, school, work and community life.*

### **What Types of Cognitive-Communication Problems can Exist?**

On the surface, many individuals appear to have little difficulty with language skills, particularly in non-stressful situations. However, with added stress from communication demands in school, work, home or community, language performance deteriorates more than what might be expected. Problems that may result include:

#### **Poor Organization of Expressive Language:**

- . Rambling conversation or written expression
- . Interruptions with irrelevant ideas
- . Minimal responses to questions with an inability to fill in details or offer other supporting information
- . Decreased ability to organize thoughts to say what is on your mind

#### **Inability to Maintain Attention:**

- . Poor listening when receiving lessons, instructions or directions
- . Difficulty staying with a task long enough to complete it
- . Inability to watch a complete movie or television program
- . Decreased ability to respond in conversation because topic is lost

#### **Difficulty with Abstract Language Skills:**

- . May not understand puns, sarcasm or humor, and may take what is said literally
- . Problems learning new information if generalizing or reasoning skills are needed

**Decreased Rate of Processing:**

- Additional time may be needed to understand what others are saying
- Slow reading rate
- Decreased ability to understand what is read
- Inability to keep up with complex sentences or vocabulary Cognitive-communication problems combine with language difficulties to make learning and applying what is learned more problematic in functional situations for persons with brain injury.

*TIP: Cognitive-communication difficulties may impact on many learning, work and social situations.*

**What Do These Changes in Communication Skills Mean?**

These changes mean that enough brain cells were damaged to affect communication skills and that some of these disabilities may be difficult to change because of the brain injury. Remediation and treatment can aid the individual with communication disabilities to be more competent in many functional situations. Oftentimes, the individual can learn to compensate for a disability by learning a new and different skill or by using assistive technology such as a computer, calculator, hearing aid or augmentative communication device.

**Who Will Assess and Provide Intervention for These Types of Problems?**

Individuals and their families should seek help from service providers who specialize in the assessment and treatment of communication disabilities. Audiologists can assess hearing. Speech-language pathologists can assess specific communication problems, offer rehabilitation and teach compensatory strategies for these problems.

If you suspect a speech, language or cognitive-communication problem, a speech-language pathologist should be consulted. A speech-language pathologist is an individual who has specialized training in the assessment and treatment of communication disorders and aids in decision making about communication intervention. These individuals may be licensed by their state and may possess a Certificate of Clinical Competence from the American Speech-Language-Hearing Association. They are employed in hospitals, clinics, universities, public schools and private practice.

Speech-language pathologists often are members of rehabilitation and education teams. In these situations, they will work closely with physical therapists, occupational therapists, neuropsychologists, physicians, nurses, social workers, educators and family members to provide collaborative and enhanced communication skills and services.

If you suspect hearing loss, an audiologist should be consulted. An audiologist is an individual who has specialized training in the assessment of hearing problems. Audiologists can help decide if amplification (i.e., a hearing aid or an assistive listening device) will improve the person's ability to hear. These individuals may be licensed by their state and may possess a Certificate of Clinical Competence from the American Speech-Language-Hearing Association. They are employed in hospitals, clinics, universities, public schools and private practice.

*TIP: If you suspect a communication problem, be sure an audiologist or speech-language pathologist is consulted and is a member of your rehabilitation or education team.*

### **What Can Families and Friends Do To Help?**

Families, co-workers, teachers and friends can play an important role in helping a person improve communication skills or learn new compensatory strategies to reduce limitations. Communication is a combination of speaking, listening, reading, writing and gesturing. All communication does not have to be spoken. Accept all forms of communication (written, gestured or spoken) that is natural and appropriate. Follow these suggestions for improving communication.

#### **General Guidelines for Helping:**

- . Communication occurs throughout the day. Be sure communication happens on a regular basis
- . Seek evaluation, treatment and collaboration from a speechlanguage pathologist if communication problems are observed
- . Use alternative means of communication such as pictures, reading, writing, gestures and facial expressions if speaking does not seem to work
- Respond to any and all attempts to communicate rather than focusing on verbal responses
- Talk about familiar subjects and do not try to introduce new ideas without assistance
- Consult with the speech-language pathologist before beginning practice of specific techniques such as rate, breath control or oral exercises
- Understand that consistency in communication is essential. Be sure every team member understands the goals and procedures to be followed
- Establish what methods for communication will be used and be sure everyone uses the same techniques. For example, if communication is to be completed by pointing to pictures, no one should be requesting written or verbal expression

- Keep conversation simple and direct, but at the correct age level of each family member
- Ask questions and expect to be involved in the rehabilitation and compensation process. Learn the compensatory strategies that are being taught
- Enjoy your communication exchanges and successes, be they large or small

*TIP: Families and friends can make important contributions in rehabilitation and treatment. Let others know that you want to play a meaningful role. Participate in planning and implementing treatment.*

### **What Are the Most Common Challenges in Communication after Brain Injury?**

Often, the most common challenges in communication are with resuming daily functioning in home, school, work or community life. Because individuals often appear to have adequate speech and language skills, expectations for adequate communication performance are higher than they should be. Family, friends and co-workers often expect people with brain injury to follow directions, express themselves appropriately or organize communication efforts quickly and efficiently. When they are unable to do so, teachers, family members, employers or peers are confused about the individual's behavior and assume disinterest or lack of competence. There are three aspects that should be considered when a communication breakdown occurs:

- The person's inability to employ adequate communication skills as a result of the brain injury
- The environment itself (i.e., is it too noisy, confusing or stimulating)
- Complications as a result of the communication partner's manner and style of communication

In some instances, the person with brain injury will be unable to adapt or compensate for his/her communication weaknesses. Therefore, people in the environment may want to consider what they can do to make the communication easier. Questions people in the environment might ask in order to help a person adapt their behaviors include:

- Did this person understand what I said?
- Was my rate of presentation slow enough?
- Did I give clear, step-by-step directions?
- Did I use puns or humor that were not understood?
- Can I help the person understand better by using pictures or writing the steps?

- Am I distracting this person with too many gestures, too loud a voice and/or too many pauses in my speaking?
- Is the environment too loud, congested, bright and/or confusing?
- Can I simplify this communication by speaking in shorter, clearer sentences?
- Can I provide a more organized explanation of what I expect to be done?
- Are there others in this situation who can help?

### **What is Different About Children and Their Communication Problems?**

A child is not a little adult. A child grows and develops over time. A child may test well at the time of the injury but may begin to demonstrate problems as he/she reaches a different developmental stage. Teachers may report:

- Difficulty in learning new vocabulary
- Decreased participation in class from pre-injury levels
- Lack of concentration
- Disruptive talking
- Use of socially unacceptable language
- Decreased reading and writing skills, especially organizational skills
- Poor interactions with peers

No one can anticipate when language or learning problems may emerge. For this reason, it is recommended that a child's language development and learning skills be monitored throughout the teenage years.

### **What Should I Do if I Suspect There are Communication Problems?**

- Write down examples of the types of communication behaviors that concern you
- Consider what problems the environment itself might be causing
- Analyze the communication manner and style of those in the environment and consider whether they could make reasonable adaptations
- Contact the medical professional you trust the most (regardless of the professional discipline). Explain your observations and concerns and ask for a referral for a cognitive-communication evaluation by a speech-language pathologist

- Expect the person with brain injury and/or a family member to be included as a team member in analyzing the communication problem and proposing solutions
- Recognize that some expectations for improvement may be unrealistic and be prepared for compensation rather than remediation
- Recall that children still are developing and be prepared for reassessment even when there does not appear to be a problem
- Ask to participate in setting goals and determining outcomes of treatment
- Be sure treatment is directed toward improving the individual's ability to communicate well in home, school, work or community activities
- Learn to advocate for communication skills to be considered when difficulty in school, work or home begins

### **References**

For further information regarding speech-language-hearing services for individuals with brain injury, contact the American Speech-Language and Hearing Association, 10801 Rockville Pike, Rockville, MD, 20852, phone: 301-897-5700 web site: [www.ASHA.org](http://www.ASHA.org) They can provide listings of speech language pathologists or audiologists in your area.

You also may contact the Brain Injury Association's Family Helpline at (800) 444-6443, email: [braininjuryinfo@biausa.org](mailto:braininjuryinfo@biausa.org) or web site: [www.biausa.org](http://www.biausa.org), if you have questions or need additional assistance.

### **About the Author...**

**Jean L. Blosser, EdD**, is President of Creative Strategies for Education. Her primary areas of interest are: management/administration; professional preparation issues; intervention strategies for traumatic brain injury; and parent-teacher training. Dr. Blosser has written many articles and presented numerous papers to professionals and family members. She is co-author of *Pediatric Brain Injury: Proactive Interventions*.

**Roberta DePompei, PhD**, is professor and clinical supervisor in the School of Speech-Language Pathology and Audiology at the University of Akron. Dr. DePompei has conducted research, written articles and coauthored a text about the impact of traumatic brain injury on the cognitive-communicative skills of the individual and the involvement of the family after injury. She has presented on these topics at state, national and international levels. She is presently co-chair of the Special Interest Group on Children and Adolescents for the Brain Injury Association.

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## **The Road to Rehabilitation**

### **Part 6 Mapping the Way: Drug Therapy & Brain Injury**

Written by Gregory O'Shanick, MD

*The Road to Rehabilitation Series (Parts 1-6) was made possible through an unrestricted educational grant from Allergan, Inc.*

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## **Introduction**

The basic unit of the nervous system is the neuron or nerve cell. Billions of these cells connect with one another to transmit information from one part of the brain to another. The messages are passed on by chemicals (neurotransmitters) released by one cell and absorbed by the next cell down stream.

With brain injury, the cell's ability to produce these neurotransmitters is reduced either by interference with production, release or absorption. These chemical changes alter the brain's ability to process information.

Medications prescribed after a brain injury improves the brain's natural ability to produce and utilize neurotransmitters. The medications act as a "cast" for the neuron to allow more normal activity during recovery. In situations where the neuron fails to recover its function, medications then are used as "splints" to allow the most "normal" neuron function possible.

## **Medication Selection is Based on Four Components**

### **Target Symptoms**

What problem is to be addressed by drug intervention? This could include problems such as: headache, insomnia, dizziness, depression and impulsivity. By defining the problem specifically, medication effect can be weighed against the likelihood of spontaneous improvement. Also, the underlying neurochemical problem can be addressed if the region of the involved area is known or if the problem has a known neurochemical deficiency.

### **Route of Administration**

Can the medication be given orally, topically, by injection, by inhalation or by some other method? The speed of absorption largely is determined by the route which the medication is administered. Problems associated with toxic levels also can be accelerated, depending on how the medication is dispensed.

### **Onset of Action**

How long does it take the medication to work? This factor depends upon the speed at which the medication crosses from the bloodstream into the neuron and the speed with which it alters the neurotransmitter activity.

### **Side Effect Profile**

All medications have side effects and the risk/benefit ratio must be considered. This includes whether the side effects potentially are permanent, such as with tardive dyskinesia, or temporary, as with dry mouth.

## **Types of Medication Used After Brain Injury**

### **Anticonvulsants**

Anticonvulsants (i.e., carbamazepine, valproic acid, phenytoin, phenobarbital, tiagabine, lamotrigine, gabapentin, topiramate) act to prevent abnormal firing patterns of neurons. This can occur as a result of direct injury to the cell or due to chemical changes around the cell. These seizures either can be generalized or focal events. Focal seizures may involve sensory, motor or behavioral regions of the brain.

One way in which anticonvulsants (i.e., benzodiazepines, barbiturates, valproic acid) may prevent seizures is by increasing the activity of an inhibitory neurotransmitter, GABA. They also may decrease the firing rates by preventing the “snowball” effect of seizure production called kindling (i.e., carbamazepine).

Anticonvulsants can be used not only to prevent seizures, but also to: (1) decrease irritability, (2) improve frustration tolerance, (3) decrease headache and (4) stabilize mood swings. Balance problems also may respond to certain anticonvulsants.

Once these anticonvulsant medications are prescribed, follow-up blood testing may be required to ensure that the concentration of medication in the blood falls within the therapeutic range. This is the level required to inhibit seizures in 95% of persons. These tests also may involve assessment of liver function and blood counts (CBC) to monitor potential toxicity of these agents.

Side effects commonly encountered with these agents include: fatigue (barbiturates, benzodiazepines), dizziness (phenytoin, carbamazepine) and gastrointestinal irritation (valproic acid). Abruptly stopping these medications without medical guidance can result in severe seizures and even death.

### **Antidepressants**

Antidepressants were first developed in the 1940s, and many refinements have occurred in the years since. Types of antidepressants include monoamine oxidase inhibitors (MAOI), tricyclics (TCA), heterocyclics and specific serotonin re-uptake inhibitors (SSRI). Novel antidepressants also have been developed which have combination effects. MAOIs (i.e., phenelzine, tranylcypromine) act by slowing the breakdown of neurotransmitters at the synapse (the junction where neural impulses are transmitted). The agents currently available require strict dietary control to prevent toxic reaction which will elevate blood pressure to lethal levels. MAOIs tend to increase energy but may cause insomnia, even at low dosages. Prescription of these agents must be supervised closely to prevent accidental drug-drug interaction (i.e., avoiding meperidine, decongestants, diet pills).

TCA's (i.e., amitriptyline, imipramine, desipramine, nortriptyline, protriptyline, clomipramine) are related closely to antihistamines and possess many of the same characteristics. They act by decreasing the reabsorption of neurotransmitters into the releasing neuron ("re-uptake inhibition").

No dietary restrictions are necessary with TCAs. They act to increase two neurotransmitters—serotonin and norepinephrine. Onset of action generally is two to four weeks after treatment is started. This allows the development of certain blood concentrations and then for the agent to cross into the neuron. Periodic assessment of blood level is useful to ensure an effective concentration.

Side effects with TCAs largely are caused by their antihistaminic and anticholinergic properties. They tend to be more sedating and commonly induce initial sleep improvement. They also tend to cause dry mouth, delayed urination, sexual dysfunction, constipation and lightheadedness. These side effects also can assist in alleviating some types of posttraumatic dizziness. Some cardiac changes may be evident, including increased heart rate and, rarely, skipped beats. TCAs also may lower the seizure threshold after brain injury. These medications can be used for: (1) explosive episodes, (2) emotional instability, (3) headache relief, (4) chronic pain management, (5) insomnia, (6) post-traumatic stress disorder and (7) typical depressive symptoms.

SSRIs (i.e., fluoxetine, fluvoxamine, sertraline, paroxetine, nefazadone, citalopram) are the newest agents in this class. SSRIs prevent the reabsorption of serotonin into the releasing neuron and increase its availability to the next neuron downstream. These powerful medications have a more rapid action onset. Usually, they have no cardiac side effects. Principle side effects relate to nausea, dizziness, fatigue and, occasionally, tremor. SSRIs also may cause sexual dysfunction. Interaction with anticonvulsants also can influence seizure threshold.

Novel antidepressants combine serotonin re-uptake inhibition with norepinephrine re-uptake inhibition (i.e., venlafaxine) or dopamine blockade (i.e., amoxapine). Side effects are similar to other agents. However, amoxapine may cause involuntary movements as can neuroleptics. Bupropion causes re-uptake inhibition of serotonin, norepinephrine and dopamine. It may be associated with overstimulation or seizures.

### **Antianxiety Agents**

Antianxiety agents (i.e., lorazepam, diazepam, alprazolam) exert their effect by increasing the inhibitory neurotransmitter, GABA. This then slows the firing rates of all neurons in the region. For thousands of years, alcohol has been used to do this as well. Currently used agents primarily are benzodiazepines, although barbiturates still are prescribed. The effect of these agents is to reduce the individual's awareness of environmental stress and disrupt memory of the events. Buspirone acts to decrease the impact of environmental events on aggression through interference with serotonin activity in the hippocampal/amygdala (memory processing) regions of the brain.

Side effects of GABA-potentiating agents include: (1) sedation, (2) short-term memory disruption, (3) muscle relaxation and (4) development of tolerance. They act to raise the seizure threshold and have some use as secondary anticonvulsants. These agents cannot be stopped without medical supervision as they can result in severe withdrawal delirium, including potentially lethal seizures. The use of ethanol with these agents greatly increases their sedating properties and can result in slowing or stopping breathing. Short-term use is appropriate if closely supervised by a physician.

### **Neuroleptics**

Neuroleptics (i.e., chlorpromazine, haloperidol, thioridazine, risperidone, pimozide) act by blocking the transmission of dopamine-stimulated nerve impulses. They rarely are used for agitation and aggressive behavior, as studies have shown that they may slow the recovery rate after brain injury. Neuroleptics may be required in severe cases of delusional thinking or hallucinations. Other similar medications are used to decrease nausea and vomiting and enhance the effect of narcotic pain relievers.

Side effects include: (1) abnormal involuntary movements, (2) weight gain, (3) low blood pressure, (4) lowered seizure threshold and (5) decreased memory. Permanent movement disorders can be seen. Newer agents such as clozapine, olanzepine, ziprasidone and quetiapine are less likely to cause movement problems, although lowered production of blood cells can be observed with clozapine.

### **Anti-Parkinson Agents**

Anti-Parkinson agents (i.e., levodopa, amantadine, bromocriptine, pergolide, pramipexole, ropinirole, benzotropine) act to increase dopamine activity or decrease cholinergic activity at the synapse. This may be beneficial in certain types of amotivational syndromes and initiation deficits. They are used to increase endurance—both cognitive and physical—and improve swallowing in certain individuals. They also can improve initiation and mood.

Side effects include: (1) agitation, (2) nausea, (3) blood pressure changes and (4) headache. High dosages also may induce hallucinations or paranoid delusions.

### **Psychostimulants**

Psychostimulants (i.e., methylphenidate, dextroamphetamine, pemoline) are used to: (1) decrease daytime drowsiness, (2) increase attention and concentration and (3) increase mood temporarily. They act by increasing the release of already-produced norepinephrine and dopamine from storage areas of the neuron. Their onset of action is within hours, and their duration is usually less than 24 hours (with the exception of pemoline). Long-term use must be monitored closely by a physician because of the abuse potential and possible lowering of the seizure threshold. These agents also can trigger paranoid thoughts and insomnia. Modafinil is a new agent that is useful in combating fatigue associated with neurological dysfunction.

### **Anticholinergic Agents**

Anticholinergic agents (i.e., meclizine, scopolamine) may be used to increase tolerance for certain types of dizziness, increase endurance and relieve insomnia at the beginning of the night. The ability of these agents to lower seizure threshold and to cause dry mouth, constipation and confusion at high doses requires close monitoring.

### **Antihypertensives**

Antihypertensives are used for headache management, aggressive behavior and impulsivity. Beta blockers (i.e., propranolol, atenolol) were the first of this class to be used successfully. Side effects include lowered heart rate and blood pressure. The agents cannot be used in persons at risk for hypoglycemia, as they mask the physical complaints.

Certain medications (i.e., propranolol) also may increase depressive symptoms. Alpha blocking agents (i.e., clonidine) are used to decrease impulsivity and blood pressure. Calcium channel blockers (i.e., verapamil) have been used to treat migraine headaches after brain injury. Their primary side effects include light headedness and constipation.

### **Narcotic Antagonists**

Narcotic antagonists (i.e., naltrexone) are a class of medications that block the brain's naturally produced opiates (endorphins) from attaching at receptor sites in the brain. These agents can be used to decrease self-injurious behavior, bulimic symptoms (bingeing and purging on food) and suicidality. These agents may decrease the craving for alcohol in those individuals with alcoholism. Side effects include potential liver irritation, confusion and headache.

### **Botox® (Botulinum Toxin Type A)**

This unique agent that is injected into muscle, prevents the release of chemical transmitters that cause muscles to contract. While other chemicals (i.e., phenol, local anesthetics) have been used to reduce this increased contraction (spasticity), Botox® provides symptomatic relief of spasticity within three to seven days of injection. Repeated dosing may be necessary to achieve the desired reduction in tone. For more information on Botox® and spasticity after brain injury, see *Part 7: Spasticity Management*.

### **Dependence on Medication**

Although not addictive in the typical sense of the word, these medicines all must be started and stopped under the supervision of a physician. If stopped abruptly, anticonvulsant and antianxiety medications can cause seizures and hallucinations. Stopping antidepressants too quickly can result in insomnia and agitation. Suddenly stopping antihypertensives can cause rebound elevation in blood pressure.

## **Side Effects**

All medicines have a main therapeutic effect, as well as side effects. Your physician can work with you to find a medicine that works, while causing the fewest side effects. Occasionally, side effects must be tolerated if no other options exist.

## **Commonly Asked Questions**

### **If I am not depressed, why do I need an antidepressant?**

Antidepressants work by increasing the amount of either serotonin or norepinephrine at the neuronal connections called synapses. In addition to depression, this effect may be useful in: (1) vascular headache management, (2) chronic pain syndromes, (3) sleep disorders and (4) balance problems. Some degree of depressed mood is expected after a brain injury because of the reaction to the changes experienced. When these mood changes are severe or include early morning awakening, appetite change, weight loss or gain and other neurovegetative symptoms, antidepressants may be indicated.

### **If I am not having seizures, why do I need an anticonvulsant?**

Anticonvulsants act to decrease the irritability of the neuron. In the most extreme situation, a seizure occurs. This irritability also can cause agitation, aggressiveness and headache. The use of an anticonvulsant may help.

### **When can I stop my medication?**

Before stopping your medications, you always should inform your physician. If you develop a serious side effect, contact your doctor or go to the nearest emergency room. Be sure to bring all your medications with you, so the physician will know exactly what you are taking.

### **Can I take over-the-counter medicines, vitamin supplements or health foods?**

You need to check with your physician first. While some medications will not be affected, others may either increase or decrease their effectiveness when combined with these substances.

### **Can I drink a beer, a glass of wine or a mixed drink with my medicines?**

Mixing alcohol with your medicines is not a good idea. Although some physicians allow moderate use of alcohol, if no previous history of substance abuse exists, any amount of alcohol may alter the effectiveness of these medications.

### **Can I use other recreational drugs?**

No. If you do experiment in this manner, you may counteract the positive effect of your medications. Discuss your thoughts with your physician to find another method to deal with stress.

### **Where can I go for more information?**

Contact the Brain Injury Association at (800) 444-6443 for physicians in your area who specialize in medication management.

**About the Author...**

Gregory O'Shanick, MD, has worked since 1981 in all aspects of neuropsychiatry and neurorehabilitation. After 10 years in academic medicine and research, he founded the Center for Neurorehabilitation Services in Midlothian, VA, where he is Medical Director. In 1996, he was asked to be the first National Medical Director for BIA. He enjoys an international reputation and has authored over 75 scientific publications in prevention, evaluation and intervention in acquired brain injury (ABI).

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For additional information about dealing with post-traumatic headaches and brain injury, contact BIA's Family Helpline at (800) 444-6443 or [braininjuryinfo@biausa.org](mailto:braininjuryinfo@biausa.org). Visit BIA's award-winning web site at: [www.biausa.org](http://www.biausa.org).

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# The Road to Rehabilitation

Part 7 ■ Traveling Toward Relief: Dealing with Spasticity & Brain Injury

Written by Cindy Ivanhoe, MD  
Elie Elovic, MD

Content reviewed by Gregory O'Shanick, MD

**Brain Injury Association of America**

# **Brain Injury Association of America**

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# Introduction

## What is Spasticity?

Spasticity is a condition that causes stiff, tight muscles, especially in the arms and legs. Individuals with spasticity often are unable to relax their muscles. As a result, movements are stiff, jerky or uncontrollable. Spasticity also may mask potential movement in the individual and it often occurs in people with brain injury, cerebral palsy, stroke, multiple sclerosis or spinal cord injury.

Some individuals also may experience spasms—sudden, involuntary muscle contractions similar to the muscle cramps athletes experience. Painful spasms may be triggered by something as minor as a simple movement of the arm or leg, skin irritation or a full bladder.

Spasticity results from a disorder of or injury to the central nervous system (CNS). The central nervous system—made up of the brain and spinal cord—works as a network of nerves connected to muscles. Complex messages continuously move back and forth between the muscles and the brain, using the spinal cord as a pathway. Normally, muscle groups in the nervous system work together so when one is flexed, its opposing muscle is relaxed. This helps maintain a comfortable level of muscle tone that provides support for the body and makes movement easy.

After a brain injury, the brain may not be able to send or receive these special messages. As a result, the system balance is disturbed so that muscles needlessly stay tight or contracted. This condition is known as spasticity. Spasticity varies from mild to severe, and is different for every individual.

## Treatment

### Why Treat Spasticity?

Spasticity does not always need to be treated. It can be beneficial if an increase in muscle tone results in better movement and increased function. However, if spasticity interferes with comfort or function, it should be treated. Spasticity can be painful and can make simple activities of daily living (ADLs)—walking, eating, dressing, bathing, going to the bathroom or transferring from wheelchair to bed—time consuming and difficult.

The increased stiffness in muscles may mean a great amount of energy is required to go about everyday activities. Sometimes, spasticity even can make these basic activities impossible to do alone. These problems affect not only an individual's self-care abilities, but also greatly increase the demands on a caregiver. In some cases, it becomes impossible for the caregivers to assist with or perform basic hygiene tasks for the individual who has severe spasticity.

When spasticity limits activity, it often causes additional medical problems such as pain, sleep disturbance, pressure sores and pneumonia. Untreated spasticity also can lead to serious orthopedic problems such as muscle contractures (a permanent shortening of muscle fibers). Contractures make joints difficult or impossible to move, can decrease blood circulation and can make positioning more difficult. While contractures can be treated with orthopedics, if the underlying spasticity is not addressed with spasticity management techniques, there is a high risk of the contractures recurring. Additionally, the joints of growing children also may become dislocated.

Spasticity can limit an individual's ability to socialize and enjoy hobbies and recreational activities. This can lead to social isolation and depression.

Treating spasticity properly can decrease health care costs by reducing medical complications and increasing functional ability and independence, as well as reducing the care and/or assistance needed. Treatment of spasticity also can improve the overall quality of life for the individual and the family.

### Team Treatment Approach

Because spasticity affects everyone differently, successful treatment requires a true team effort among the individual with spasticity, family members, caregivers and health care professionals. At a minimum, these teams should include the doctor (physiatrist, neurologist), individual with spasticity, family members, care providers, nurses, psychologists, physical and occupational therapists, social workers and insurance staff members. It is important that the team includes health care professionals who have experience working with individuals with brain injury.

The first step in getting quality treatment is recognizing that something can be done to relieve spasticity. Many treatment options are available today. Finding a qualified medical professional to develop a specific treatment plan based on the individual's goals and abilities is the next step. It particularly is important to identify a medical professional who has a clear understanding of the special needs and unique characteristics of individuals with brain injury.

## Goals of Treatment

There are a number of treatment options available for spasticity. Some treatments are more appropriate for certain types of individuals than others. Before starting any treatment, it is important for the individual, the family and the health care team to agree upon realistic goals so that the health care team can recommend the treatment most likely to achieve those goals. This process can help avoid the disappointment that may occur if treatments do not produce the results that the individual or family had hoped for.

A common goal for treating spasticity is to reduce painful muscle contractures. Other goals may depend on the muscles or muscle groups affected and how spasticity has affected an individual's movement and ADLs. For those who can walk, the treatment goal may be to improve their gait (walking) or simply to reduce spasticity in order to minimize the energy needed to walk. For individuals who cannot walk or who have more severe spasticity, treatment goals may include sitting more comfortably, feeding themselves or sleeping through the night. For those individuals unable to care for themselves, the goal often is to make caregiving easier and less time consuming, as well as to prevent medical complications such as pressure sores and pneumonia.

## Treating Spasticity

There are many treatments available for spasticity and outcomes are best when the treatment plan is customized for the specific patients' needs. Factors such as severity, time post-onset of the condition causing spasticity, medical stability, location, extent, prognosis and speed of complication development all play a part in the decision-making process for treating spasticity. Therefore, it is critical that the treatment team have extensive knowledge and experience in treating individuals with spasticity.

Understanding spasticity and knowing as much as possible about the benefits and drawbacks of all available treatment options is important. The health care team can work with individuals and their families to assess which treatments might be most appropriate for meeting specific treatment goals. Treatments for spasticity can be used alone or in combination and not all treatments are appropriate for every person.

## Removal of Conditions that Can Cause an Increase in Spasticity

People whose central nervous systems have been injured often have medical problems that can increase their spasticity, including skin ulcers, DVT (blood clots), kidney stones, infections and even something as minor as an ingrown toenail. A proper diagnosis and optimal treatment of these conditions is critical for successful spasticity management. Individuals with central nervous system disease or injury commonly use various medications. Some of these medications actually can make movement more difficult. The health care team should be aware of the patient's overall medical status and goals to combat spasticity effectively.

## Physical Therapy and Occupational Therapy

For most individuals, these therapies usually are the first action taken against spasticity. The goals of physical and occupational therapy are stretching muscles to maintain range of motion and prevent muscle shortening that can lead to contractures, strengthening appropriate muscles and learning ways to carry on daily activities more effectively. Physical and occupational therapists also can help individuals with assistive devices like walkers, motorized wheelchairs and instruments to help them cope with speech defects.

Frequently, individuals with spasticity require different techniques to gain maximum function and motor learning. These different techniques can include: serial casting, inhibitory casting, weight bearing and forced use activities in conjunction with Botulinum toxin injections, nerve/motor blocks, Intrathecal Baclofen Therapy™ and orthopedic procedures.

## Orthotics

Orthotics can be used in combination with other methods of spasticity management. Casts and splints may be helpful in improving range of motion in the arms and legs. By keeping the limb in a stretched position, the muscles slowly lengthen to improve range of motion at the joint. This helps prevent muscle contractures. Orthotic devices also provide joint support and stability, allowing for safer movement. They often are used in combination with other therapies such as nerve blocks and intramuscular injections.

## Oral Anti-Spasmodic Drugs (Pills)

Oral medications can improve spasticity in some individuals with mild to moderate spasticity. Because they circulate throughout the body in the bloodstream, these medications affect nearly all muscles. All oral medications used to treat spasticity have the potential for side effects that should be weighed against their benefits. The most effective dosage will depend on striking a balance between the drug's positive and negative effects. After brain injury, people are even more likely to experience the sedating affects of these medications.

*Baclofen (Lioresal®)* is a common medication used to treat spasticity. Baclofen is an anti-spasmodic that works within the spinal cord, the pathway for messages between the brain and the nerves. Side effects may include: hallucinations, confusion, sedation, loss of muscle tone, poor muscular coordination and weakness in non-affected muscles. It also takes large amounts of the medication to actually get a small amount into the CNS. Baclofen should not be discontinued suddenly because sudden withdrawal of the medication can result in hallucinations, psychoses and/or seizures.

*Diazepam (Valium®)* is absorbed rapidly, takes effect quickly and stays in the body much longer than baclofen. Although both drugs work on the CNS, diazepam is more likely to produce sleepiness, unsteadiness or short-term memory difficulties. In addition, some people can become dependent physiologically on the medication. Tolerance also can develop, so larger doses may be needed over time to achieve the same effect.

*Tizanidine hydrochloride (Zanaflex®)* is an anti-spasmodic drug that works on the CNS to decrease the muscle reflex that causes muscles to contract. It may cause increased drowsiness and also can cause liver damage. Other side effects can include dizziness, low blood pressure and dry mouth. In addition, there have been only a few publications on its use and side effects in children and young adults.

*Clonidine* is a blood pressure medication related to tizanidine that also has shown efficacy in the treatment of spasticity. There have been numerous publications describing its effectiveness or usefulness in treating spasticity of spinal cord origin. Its use with spasticity secondary to acquired brain injury (ABI) is more controversial, as it may have the potential to slow motor recovery. Additionally, there only is very limited literature reporting benefits to this population.

*Dantrolene sodium (Dantrium®)* acts on the muscles themselves rather than on the CNS. It weakens spastic muscles, but it also can affect normal muscles. Dantrium is less likely to cause sleepiness and confusion. A serious side effect can be liver damage, especially in females and those over 35 years of age. Other side effects may include: drowsiness, weakness, nausea, vomiting, dizziness, diarrhea, depression and blood abnormalities.

## Intramuscular Injections

These medications usually affect only the injected muscles and should not cause side effects to the CNS. When the goal is to reduce spasticity in one or two muscles or muscle groups, injected medications are desirable because of the length of relief they provide and their low side effect profile. Injections may not be adequate to treat individuals with severe diffuse spasticity, as these individuals can require higher doses than are advocated currently. However, injections may be used in these cases in combination with the other treatments discussed. The effects of injections will vary with dosing, muscle selection and administration of other interventions.

*Botulinum Toxin A (Botox®)* is derived from the bacteria causing botulism. Injected in small doses into the affected muscle, it weakens the muscle by blocking the chemical impulses that cause the muscle to contract. While oral medication affects multiple muscle groups in the body, Botox® is most effective for managing spasticity in specific limbs or small muscle groups. Injections can relax affected muscles for three to four months before the effects wear off, though individual effects will vary.

Side effects include: tenderness at the injection site, local weakness and possible formation of antibodies that could make the injections less effective over time. Because tolerance can develop, there are limitations on how often and how much toxin can be injected. While the medication has not yet been approved by the FDA for spasticity treatment, it is used

routinely and the procedure is tolerated very well. At this time, experts recommend that individuals receive injections no more than once every three months and with the lowest dose possible to minimize the probability of developing tolerance to the toxin. Some individuals with dystonia (disordered tonicity of muscle) have been treated for many years and have not developed tolerance.

*Botulinum Toxin B (Myobloc®)* is the second product that recently has been released by the bacteria causing botulism. There is evidence that it is effective in the treatment of muscle overactivity secondary to cervical dystonia for both Botulinum toxin A responsive and A resistant patients. At the time of this writing, no publications discussing its use in spasticity have yet to appear. However, its potential utility as an intramuscular anti-spasticity agent, especially in the population who are resistant to the A toxin, will be explored in the near future.

*Phenol* is a type of alcohol that chemically blocks nerves in the affected muscles to reduce spasticity. It is similar to Botox® in length of effectiveness and type of spasticity it treats. Phenol injections may cause pain or a burning sensation when injected. Possible complications include: bleeding, swelling, pain, changes in sensation and the slight risk of a blood clot in the arm or leg that is injected. Effects of the injections usually last from two weeks to six months. In some cases, however, phenol injections have resulted in permanent effects.

### **Intrathecal Baclofen (ITB®) Therapy**

Using a small pump surgically placed under the skin, this therapy delivers a liquid form of *Baclofen (Lioresal® Intrathecal Baclofen injection)* directly to the fluid surrounding the spinal cord. The medication is delivered directly to the site of action at the spinal cord. It does not circulate throughout the body in the bloodstream like an oral drug, so it relieves spasticity with much lower doses. This helps reduce or eliminate the side effects common with oral baclofen while at the same time producing a greater response. ITB Therapy is effective for individuals with generalized spasticity or spasticity in large muscle groups. It can be extremely beneficial for people with dynamic tone (tone that increases with movement). It also can lead to dramatic functional improvements for individuals.

Prior to implant of the ITB pump, candidates undergo a trial to see if they would benefit from the therapy. Once implanted, the dose of ITB Therapy can be adjusted from outside the body using a computer-like programmer to deliver different amounts of medication at different times of the day, as needed. Pump refills are required every one to three months. The therapy is nondestructive and fully reversible. The most common device-related complications are kinks, dislodgements or breaks in the catheter that delivers the drug from the device into the spinal fluid. The most common drug side effects are overly loose muscles, sleepiness, upset stomach, vomiting, headache and dizziness.

ITB Therapy was approved by the FDA in 1992 for spasticity resulting from spinal cord injury and in 1996 for spasticity due to injury to the brain. ITB Therapy is most useful in the treatment of severe spasticity in the legs and trunk. Originally, patients waited a year post-injury to have a pump implanted. Today, there is a growing interest in implanting pumps earlier, thereby avoiding some of the complications of prolonged spasticity.

Other agents also have been trialed intrathecally. Clonidine, morphine and fentanyl all have demonstrated some efficacy when administered intrathecally. Trials with other agents, including tizanidine, currently are underway and may become more widespread in the future.

### **Neurosurgery**

These procedures include cutting nerves (neurectomy) or nerve roots (rhizotomy) to relieve spasticity. Most often, rhizotomy is used to relieve spasticity in children with cerebral palsy. In this procedure, rootlets of sensory nerve roots, which run from the spastic leg muscles to the spinal cord, are stimulated electrically. Those responding abnormally are cut. Appropriate candidates for rhizotomy include: 1) individuals with enough underlying strength to maintain and improve their function once spasticity is relieved; 2) non-walking individuals with spasticity that interferes with sitting, positioning and care; and 3) individuals whose severe spasticity causes hip dislocations or bone contractures. If an individual needs some spasticity to stand or walk, rhizotomy may impair function and may not be an appropriate treatment. Neurosurgeries are destructive, permanent procedures.

### **Orthopedic Surgery**

Some individuals may be candidates for orthopedic surgeries to correct deformities resulting from spasticity or to aid the effects of other spasticity treatments. These procedures include: (1) tendon lengthening to reduce spasticity by relieving tension on the muscle; (2) tendon transfer to reduce spasticity by repositioning the tendon; (3) osteotomy to correct bone alignment; and (4) severing tendons (tendonotomy). Tendonotomy means cutting the tendons in affected limbs to reduce contractures and spasticity, increase motion and, in some cases, improve functional use of the limb. The most common procedure performed is the Tendon Achilles Lengthening (TAL), which allows individuals to walk more normally by getting their heels on the ground. Outcomes after orthopedic procedures are best when the spasticity is controlled well. Additionally, orthopedic surgery can be used in combination with ITB with the general recommendation being that if both are contemplated, the pump should be placed prior to the orthopedic interventions.

## Resources

A number of health care and rehabilitation facilities offer clinics specializing in spasticity management. Look for a center that offers comprehensive spasticity management. These centers have specially trained staff and provide the most treatment options. Checking with the local hospital may be a good start.

Managing spasticity in individuals with brain injury requires a team effort among the individual, family members, caregivers and an integrated team of health care professionals. Depending on the case, the team may include the doctor (physiatrist, neurologist), the individual with spasticity, family members, care providers, nurses, psychologists, physical and occupational therapists, speech therapists, social workers and insurance staff members. It is important that the team includes health care professionals who have experience working with individuals with brain injury, who can appreciate the big picture and who can work together with the individual and family to set and reach appropriate goals.

Health care professionals should work with the individual and family to explore various treatment options and decide the best course of action for the individual. Before starting any treatment plan, it is important for the team to set realistic goals for the individual. Family members can enhance the chance of successful treatment by encouraging communication among team members, tracking the individual's progress against the goals set and providing as to their needs.

## About the Author...

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For additional information about dealing with post-traumatic headaches and brain injury, contact BIA's Family Helpline at (800) 444-6443 or [familyhelpline@biausa.org](mailto:familyhelpline@biausa.org). Or visit BIA's award-winning web site at: [www.biausa.org](http://www.biausa.org).

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### Road to Rehabilitation Series

1. Pathways to Comfort: Dealing with Pain and Brain Injury
2. Highways to Healing: Post-Traumatic Headaches and Brain Injury
3. Guideposts to Recognition: Cognition, Memory and Brain Injury
4. Navigating the Curves: Behavior Change and Brain Injury
5. Crossing the Communication Bridge: Speech, Language and Brain Injury
6. Mapping the Way: Drug Therapy and Brain Injury
7. Traveling Toward Relief: Dealing with Spasticity and Brain Injury
8. Journey Toward Understanding: Concussion and Mild Brain Injury

For the individual with brain injury and his/her circle of support (i.e., family members, significant others, friends and co-workers) brain injury is a complex and often tumultuous journey. Although there are broad issues affecting ALL individuals with brain injury, both the road to rehabilitation and the outcome experienced by each individual are unique. In this series of brochures, BIA seeks to educate individuals and organizations about rehabilitation after brain injury. Some individuals with brain injury may face challenges in all of these areas, while others may experience problems with just a few of them. Regardless, the information in these brochures is crucial to provide those affected by brain injury, as well as the individuals and organizations treating them, with a basic understanding of the complex challenges following brain injury. For additional information about any of the topics covered in The Road to Rehabilitation Series, contact BIA's toll-free Family Helpline at (800) 444-6443 or visit their web site at [www.biausa.org](http://www.biausa.org).



# **The Road to Rehabilitation**

## **Part 8: Journey Toward Understanding: Concussion & Mild Brain Injury**

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**Ronald C. Savage, PhD**

**Content reviewed by Gregory O'Shanick, MD**

**Brain Injury Association of America**

***The Road to Rehabilitation Series* is sold as a set of eight brochures. The Bookstore can be found on the Brain Injury Association website: [www.biausa.org](http://www.biausa.org)**

# Introduction

*Three little monkeys jumping on the bed.  
One fell off and bumped his head.  
Took him to the doctor and the doctor said,  
“That’s what you get for jumping on the bed!”*

This nursery rhyme tells a story about concussion—the bumps, bangs and shakings to the brain that many adults and children experience. Unfortunately, just like the monkeys jumping on the bed, professionals may not understand concussion well enough to offer support and to help individuals who sustain concussions. People with concussions may just try and “shake it off” and, thus, not be evaluated and treated properly by professionals. It is not uncommon for individuals to be sent home from emergency rooms (ERs) with no follow-up care or to end up with long-term problems that no one understands. This booklet will define concussion, present the common symptoms of concussion and discuss ways to help people who sustain concussions.

Each year, it is estimated that approximately 1.5 million people experience concussions. Vehicular crashes (cars, motorcycles, bicycles), sports/recreational activities (football, hockey, playgrounds), abuse/assault (shaken baby syndrome, beatings), falls (young children and the elderly) and other events all have been implicated. It is easy to see that almost any activity can put a person at risk for a concussion. It is a little surprising that people do so well avoiding concussions and equally not surprising that many of us have had concussions.

It is important to note that concussions clearly are associated with lifestyle and parallel other similar lifestyle injuries. If you are involved actively in sports that put your body at risk for muscle pulls, strains, sprains and broken bones, then your chances of a concussion also are great. The Centers for Disease Control and Prevention (CDC) estimates 300,000 sports-related concussions in the United States each year. The more risk to your body, the more risk of serious harm and permanent damage, and the greater the chances that a concussion or more permanent brain injury can occur.

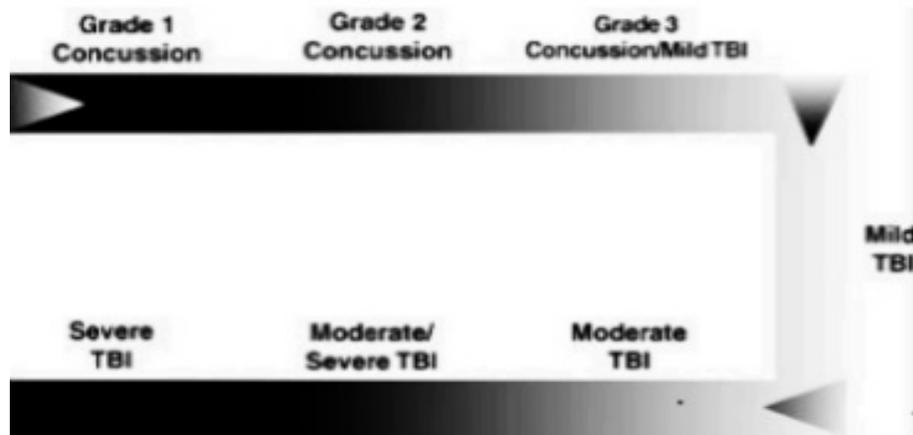
If your job involves heavy labor in farm or construction settings, your chances of physical injury increase and the chances of a concussion increases as well. The use of substances, such as alcohol, that alter your judgment and coordination about everyday activities, like driving or even walking, put you at risk for physical injury and, therefore, at similar risk for a concussion or more serious brain injury. Children—especially younger children—are susceptible to sustaining concussions from falls, play activities and abuse. Lastly, older individuals with balance problems may be prone to falls that can result in not only broken hips, but concussions as well.

## **What is Concussion?**

It is important to understand that a concussion is a physical injury to the brain that causes a disruption of normal functioning just like any other physical injury disrupts your normal functioning. For example, some ankle injuries (i.e., sprains and fractures) are more disruptive than others, just as some brain injuries are more disruptive than others. The better we understand any injury, the better our chances are for a speedier and healthier recovery.

There is some confusion as to the definition of a concussion and the definition of a mild traumatic brain injury (MTBI). Brain injury can be viewed along a continuum that incorporates concussion, mild brain injury, moderate brain injury and severe brain injury. Each type of brain injury varies depending upon:

(1) whether the person was unconscious, (2) how long he/she was unconscious, (3) the length of their amnesia, (4) the resulting cognitive, behavioral and physical problems and (5) the recovery. Viewed as a continuum, the severity of brain injuries can be represented as follows:



As one can see, the definition for a Grade 3 concussion and a MTBI tend to overlap on this continuum.

To further clarify, a concussion is defined as a trauma (i.e., a blow to the head or a serious whiplash) that induces an alteration in mental status (physical or cognitive abilities) that may or may not involve a loss of consciousness. Concussion as detailed by guidelines developed by the American Academy of Neurology (AAN) and the Brain Injury Association (BIA), commonly is divided into three different types.

### **Grade 1 Concussion**

- Person is confused but remains conscious
- SIGNS: Temporarily confused, dazed, unable to think clearly, has trouble following directions
- TIME: Symptoms clear within 15 minutes

### **Grade 2 Concussion**

- Person remains conscious, but develops amnesia
- SIGNS: Similar to Grade 1
- TIME: Symptoms last more than 15 minutes

### **Grade 3 Concussion**

- Person loses consciousness
- SIGNS: Noticeable disruption of brain function exhibited in physical, cognitive and behavioral ways.
- TIME: Unconsciousness for seconds or minutes

It is important to note that a person can sustain a concussion (Grades 1 & 2) without losing consciousness. A Grade 3 concussion involves the loss of consciousness, even if only briefly. As defined by the American Congress of Rehabilitation Medicine, MTBI is a traumatically induced physiological disruption of brain function as manifested by some or all of the following:

- Any period of loss of consciousness
- Any loss of memory for events immediately before or after the incident
- Any alteration in mental state at the time of incident
- Focal neurological deficits that may or may not be transient but does not exceed:
  1. Loss of consciousness of approximately 30 minutes or less
  2. An initial Glasgow Coma Scale score of 13-15 after 30 minutes
  3. Post-traumatic amnesia (PTA) of no more than 24 hours

If concussion and MTBI are seen as part of the brain injury continuum, with Grade 3 concussion and MTBI overlapping, one can get a better understanding of how these definitions compliment each other and enhance our understanding. BIA estimates that approximately 75% of all brain injuries fall in the “concussion-MTBI continuum.”

### **The Functional Mechanics of Concussion**

Two mechanisms currently are believed to underlie the changes following concussion. In the first, a sudden movement or direct force applied to the head can set the neural matter of the brain in motion even though the brain is well protected in the skull and very resilient. This motion squeezes, stretches and sometimes tears the neural cells, changing the precise balance and distance the cell’s axons and dendrites maintain to transmit or process information.

The second mechanism involves changes that occur in the neuron’s ability to produce energy for the cell’s vital functions in structures called mitochondria. An initial increase in energy production occurs followed by a dramatic decrease that affects the ability of the cell to produce structural proteins to preserve the diameter of the axon. This change occurs gradually after the time of impact and may be responsible for the delay in symptoms sometimes observed.

The changes that occur affect the electrical or chemical aspects of neural cell functioning and result in unusual processing of normal information. (For this reason, radiologic studies that look at the structure of the brain, such as CT scans and MRI, are most frequently read as normal after concussion/MTBI.)

This actually is quite adaptive because the brain cells automatically keep working to reconnect or establish normal impulse transmission. Even the loss of consciousness is adaptive, because the brain shuts down all unnecessary functions until the most important life sustaining neural adjustments are made. Unfortunately, sometimes these neural adjustments cannot be made quickly enough and death can occur.

As a person recovers, the cells re-establish the precise balance needed to ensure effective information processing, but this may mean some compensation or adjustments to the neural cell’s original alignments. The more often neural cells must compensate or adjust to injury, the more likely the task takes longer and may not be as complete. For example, when a person sprains or fractures an ankle, professionals recommend cold/heat treatments, rest and supports (i.e., cast, brace) and specific exercises to help the ankle adjust to the injury and recover maximal function. Depending on the severity of the ankle injury (i.e., sprain, fracture) and what is required after recovery (i.e., long distance running, ballet), the severity of the injury to the ankle can disrupt a person’s life.

Obviously, a human brain is much more complicated than an ankle. Yet, similarly, rest, supports (i.e., compensations, modifications) and “exercises” (i.e., therapies, education) for the brain may be recommended to rehabilitate and restore useful function. Depending on the severity of the concussion and what the person needs to do (i.e., care for a family, return to work or school, manage a large company), a concussion can disrupt a person’s life for a short period of time or even longer.

To review, a concussion causes a disruption of normal brain function that may be a temporary inconvenience or result in permanent changes in brain function. Where there are complicating factors, the disturbance in brain function can be fatal. Because of the potential life-threatening danger associated with brain injury, the severity of any brain injury—including concussion—is determined at the time of the injury, based on measures of physical, cognitive and behavioral responsiveness.

Again, the three categories commonly used to describe brain injury—mild, moderate and severe—indicate only how seriously impaired the person was at the time of the injury. Thus, on the brain injury scale of severity, a concussion usually is classified as a MTBI because the alterations in brain function are not severe enough or do not last long enough to be classified as moderate or severe brain injury.

In the moderate and severe classifications, there appears to be direct damage to the brain’s neural network with long-term difficulties related to the sites of the damage. The long-term effects of MTBI on brain cell recovery and functioning and behavior vary across individuals. However, for most individuals, no long-term neuronal changes are noted after three to four months and the cognitive and behavioral adjustments return to normal.

Exceptions to this rule exist. Studies suggest that age (i.e., 40 years or older), the presence of a systemic disease (i.e., diabetes mellitus), and possibly female gender affect the recovery process. Other risk factors for delayed recovery include a history of previous brain injury or when situational and personality factors play a role in recovery. For example, individuals who sustain a second concussion while still symptomatic from the first one may sustain what is termed “second impact syndrome.” This condition is very serious and can result in lifelong impairments, coma and even death. Individuals who sustain a series of multiple concussions over time (i.e., boxers, abused children) may be left with permanent impairments and disabilities. People who have mental health issues or other disabilities (i.e., attention deficits, learning disabilities) may find that a concussion further complicates their behavioral and learning challenges.

Also, even litigation issues may complicate a person’s recovery. The symptoms of concussions cover a wide range of perceptual, sensory, cognitive, emotional and behavioral features.

### **Early Symptoms:**

- Headache
- Dizziness or vertigo
- Lack of awareness of surroundings
- Nausea with or without memory dysfunction
- Vomiting

**Later Symptoms:**

- Persistent low grade headache
- Lightheadedness
- Poor attention and concentration
- Excessiveness or easy fatigue
- Intolerance of bright light or difficulty focusing vision
- Intolerance of loud noises
- Ringing in the ears
- Anxiety and depressed mood
- Irrability and low frustration tolerance

Many of the symptoms listed above are common to a variety of other natural human experiences. Feeling scared or anxious can make our vision change and cause dizzy feelings and numerous fight or flight reactions. Muscle cramps in the neck can give us headaches, just as not having our usual dose of caffeine causes headaches. A virus can make us feel “spaced-out” and affect our balance. Depression can affect our cognitive abilities and memory. Being angry over changes due to an injury such as a broken arm can make us irritable and affect our motivation. And, as with concussion, if everyone else feels you “should be over it by now,” being treated unfairly may cause hopelessness that makes it difficult to concentrate and sleep.

**Why is there so much variation in symptom presentation?**

This variation can best be explained because people differ and their perceptual experience of sensations such as pain and distress remains subjective. Without a technology (i.e., more sophisticated CT/MRI scanning technology) to measure these individual experiences, it remains difficult to determine when the brain’s coping or healing has taken place and when the individual’s reaction to the process has left perceptual and learned phenomena. Thus, we need to monitor the symptoms of concussion in order to monitor recovery. The following checklist can help individuals and their families monitor their recovery one to three months after a concussion so they can report this information to their physician or therapist better. Symptoms that persist beyond the usual recovery time for concussion need to be evaluated and treated more carefully.

<b>Physical Symptoms</b>	<b>Cognitive Symptoms</b>	<b>Behavioral Symptoms</b>
Headache, dizziness, lightheadedness	Confusion, in a “fog,” has befuddled expression, gets mixed up about time and place	Restless, irritable, fussy
Vomiting or nausea	Attention or concentration problems, inability to do more than one thing at a time, unable to return to a task if interrupted	Acts without thinking
Numbness or tingling	Memory problems, forgets things	Becomes upset easily, loses temper
Balance problems, clumsiness, drops things, trips often	Takes longer to get things done or complete assignments	Sadness, depressed mood

Physical Symptoms (cont'd)	Cognitive Symptoms (cont'd)	Behavioral Symptoms (cont'd)
Fatigue, tires easily, needs extra sleep, drowsiness, trouble falling asleep or staying asleep	Has problems organizing thoughts or words, misunderstands things	Anxiety, nervousness
Sensitivity to light and noise		
Blurry vision		
ringing in ears		

### **Why do some people adjust better after a concussion than others?**

Research in cognitive-behavioral therapy supports the notion that: (1) looking at the positive aspects of recovery, (2) taking steps to gain control of your rehabilitation and (3) knowing that fundamental healthy behavior requires a focused rehearsed plan all can contribute to dealing better with the many sensations and feelings often following concussion. Concussion needs to be taken seriously and modifications to a person’s life (i.e., home, work, school) need to be made during the recovery period. Just because a person “looks great” does not mean that they are recovered fully. Having a good plan for recovery and knowledge about concussion helps individuals feel more in control and lessens their anxiety.

### **Why do concussion symptoms change over time?**

It now appears that during the first months after concussion the brain begins to heal and evidence suggests that there is little trace of brain damage after three to four months. During this period of time, sleep patterns return to normal, sensations mirror the brains recovery and efforts to return to normal and develop your sense of self are influenced by the rehabilitation process. For example, many strange sensations accompany recovery from a sprained or fractured ankle, including pain from the efforts a person makes to accommodate the recovery time (such as muscle atrophy), as well as sleeping and exercise changes due to the limitations. Brain function is much more complex to understand and monitor. Yet, just as an ankle can “return to normal” over time, so can the brain after concussion.

### **Why can’t professionals tell if there is permanent brain injury over time?**

Without doing an autopsy, brain function only can be estimated. For example, neuropsychological testing can provide information about what a person might be able to do at this point in time, but without the same information from before the concussion, it only is possible to estimate how a concussion affected performance. Many professionals use various tools to help them understand the degree of brain damage (i.e., CAT scans, MRIs, neuropsychological batteries, neurolinguistic assessment, functional behavioral analysis), but these tools only are approximations and it is difficult to predict the total impact a brain injury may have on a person’s life. The best “predictor” is the person with the injury working with a dedicated team of professionals to identify and compensate for permanent damage.

### **Is permanent brain damage always bad?**

This is a trick question because the easy answer is that damage always means a loss of brain cells. Yet, many people can attest that the loss of brain cells does not mean that they themselves are “lost.” Rather, many individuals have found the strategies and techniques they have used to cope with brain injury have been helpful in assisting them to become the person they felt they wanted

to be all along—happy, loved, productive and important. The experience of coping with a rehabilitation or treatment program has helped them: (1) appreciate their talents, (2) give up bad habits and (3) become more mindful of what they truly wanted out of life. This is not said to minimize the tremendous changes brain injury causes for people and their families, but rather to emphasize the importance of good treatment programs and community supports to help people re-define their lives.

### **Treatment Recommendations**

*The only cure for brain injury is prevention.* Obviously, the treatment of concussion starts with prevention. Thoughtful preparation before activities— knowing your limits; minimizing risk to one’s head by wearing protective gear such as seat belts, helmets, hard hats; and being substance free when activities require concentration such as driving, bicycling, swimming, boating and skiing—all will reduce the likelihood of injury. Unfortunately, concussions often are difficult to prevent even with careful preparation and protective gear.

Immediately after a brain injury, emergency care may be required. Since lifethreatening complications—usually due to brain swelling and bleeding—can occur from any brain injury regardless of the type, all brain injuries must be taken seriously. The proper assessment of concussion by emergency medical professionals and physicians is critical.

AAN and the BIA have developed a clear, scientifically-based set of guidelines for the medical management of concussion in sports that is used by team physicians, coaches and athletic trainers that easily can be adapted for all concussions. Thus, after the type of concussion has been determined, management guidelines are implemented. If an adult sustains a Grade 1 or 2 concussion, it may be wise for that person to rest for two to three days before returning to regular activities and not operate a motor vehicle for at least a week. If a child crashes a bicycle and the physician has examined and given them a clean bill of health, it is wise to keep the child off the bicycle for a week. As always with children, the rule should be that if it has wheels, you need a helmet.

The potential danger with concussion is sustaining a second one before allowing the brain time to rest and recovery from the first one (as we would for a broken ankle). The chart below summarizes AAN’s management recommendations for athletes returning to play after concussion, but reworded for the general audience. Please remember that all concussions potentially are serious and individuals should be examined by their physicians if there is any doubt about their safety.

#### **Grade 1 Concussion Management Guidelines**

If the person has no symptoms or mental status abnormalities 15 minutes after the injury, he/she can resume normal activities. All symptoms from the concussion must have disappeared, first at rest and then with exertional testing, before the individual can return to regular activities.

#### **Grade 2 Concussion Management Guidelines**

The individual should refrain from activities for at least one week, again only after the person is asymptomatic at rest and during exertion. Additionally, a physician should perform a neurological exam before the individual is allowed to go back to regular activities. If the individual experiences a worsening in headaches and other concussion symptoms and/or these symptoms last longer than a week, a CT or MRI is recommended.

### **Grade 3 Concussion Management Guidelines**

One month should be the minimum period for an individual to return to rigorous activity. For an individual with a brief loss of consciousness (i.e., seconds), he/she can return to regular activities only after being asymptomatic for at least one week. For a person who had a prolonged loss of consciousness

(i.e., minutes), he/she can resume normal activities no sooner than after two weeks of rest. A thorough neurological examination and a neuro-imaging study (i.e., CT, MRI) should be performed on all individuals who have been rendered unconscious for brief periods of time. The individual should be admitted to the hospital if any signs of pathology are detected and/or the mental status of the person remains abnormal.

Recovery after concussion—just like a sprained or fractured ankle—takes time. An individual with a broken ankle would not go out the next day and run a marathon. That individual likely would take time out from work, rest and put the leg up, use crutches, attend therapy, if necessary, and allow the ankle time to recover. Too often after concussion, many individuals immediately return to work or school, push themselves to think as well and as quickly as they did before and expect that in a day or two they are recovered fully. One of the problems with concussion is that people try and “get back on the horse” too quickly. The danger in doing this is that the person could sustain a second concussion (i.e., the athlete returns to the game; the child gets back on his/her bicycle; the person resumes driving a car) that could cause more serious injury to the brain. Or, if individuals push themselves to perform and/or are expected to perform by their colleagues and family too soon after the concussion, the symptoms may become exacerbated.

After a concussion, it is wise for people to modify their lives by: (1) reducing their workloads; (2) building in rest periods; (3) giving more time to finishing projects; (4) developing a written plan to refer to when confused or uncertain; (5) using a notebook/calendar to write things down and check-off when completed; (6) writing down schedules with time, place and person and (7) avoiding the use of alcohol or other substances that may slow recovery. It also is important to monitor symptoms over the next one to three months and report this data to one’s physician and other treating professionals. Family members can become more knowledgeable about concussion and help the person make accommodations, monitor symptoms and ensure that—just like with a broken ankle—the person is given ample healing time. The use of other professionals, such as a neuropsychologist, can help through testing to determine a person’s strengths, needs and preferences. Psychologists and counselors may be extremely beneficial in helping people with more serious injuries to understand and adjust to any changes caused by the concussion. BIA, its chartered state affiliates and support groups may provide the person with education about concussion and where to go for additional help.

### **Conclusion**

Concussion is the most common of all brain injuries. It needs to be better understood, evaluated and treated. Individuals who sustain concussions may experience an array of symptoms, both short- and long-term. The important thing is to take any concussion seriously and recognize that recovery is dependent on many things.

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Ronald C. Savage, EdD, has worked with children, adolescents and young adults with neurological injuries and disabilities for over 25 years. Presently, Dr. Savage is President of the North American Brain Injury Society ([www.nabis.org](http://www.nabis.org)). He is the former Senior Vice President of Behavioral Health and Rehabilitative Services at The May Institute in Massachusetts and the former Director of Clinical Services for Rehabilitation Services of New York and the company's four rehabilitation facilities. In addition, Dr. Savage has taught at the elementary and secondary school level as a classroom teacher and as a special educator, as well as teaching at several colleges and universities. Dr. Savage has presented at over 200 conferences, training seminars and grand rounds presentations in the past four years. He has published numerous articles, chapters, manuals and books on children, adolescents and adults with traumatic brain injuries and other neurological disabilities.

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For additional information about dealing with post-traumatic headaches and brain injury, contact BIA's Family Helpline at (800) 444-6443 or [braininjuryinfo@biausa.org](mailto:braininjuryinfo@biausa.org), or visit BIA's award-winning web site at [www.biausa.org](http://www.biausa.org).

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